

# Children's Coalition Newsletter



Children's Palliative Care Coalition of Michigan

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December 2016

## Coalition Moves Forward but Faces New Challenge

*More than 100 medical and other professionals, as well as interested parents, attended the inaugural conference of the Children's Palliative Care Coalition of Michigan in November 2016. Adopting an ambitious agenda to improve care across the state, the new Coalition faced an unanticipated challenge.*

Following the agenda, attendees created committees to advocate for needed changes, develop respite resources for caregivers, support bereaved parents, advance pediatric perinatal care, and promote awareness of palliative care to professional caregivers and the community.

Speaker Jeff Lycan, RN, was the first to draw attention to the challenge. Addressing the conference on the need to set goals and objectives, he touched on what had been the unlikely prospect of the Affordable Care Act now being "repealed and replaced".

Once a remote legislative possibility, this had become an executive promise after the presidential election three days earlier. Elections affect us all, even such an apolitical organization as our new Coalition.

When enacted as law in 2010, the Act brought major advances in insurance for children. Perhaps the most important in respect of palliative care is the requirement that payment for concurrent curative treatment should not be denied. Although only enforceable for government programs like Medicaid, it has been widely influential. Parents are now more often able to accept palliative care without fear they may give up hope for cure.

Other clauses of the Act affecting children have broader application. These include insurance coverage for pre-existing conditions, banning lifetime limit on benefits, and enabling young adults to continue on their parents' health insurance until age 26. The Act also enabled states to broaden eligibility for Medicaid. The Medicaid Expansion (Healthy Michigan Plan), which covers youth and young adults who have aged out of traditional Medicaid, is a good example.

Our Advocacy Committee, led by Dr. Jane Turner of Michigan State University, was created with the intention of securing legislative advances similar to those obtained by coalitions in other states. It now it found itself having to consider the defense of an existing piece of legislation.

To contemplate such a contingency is not to be judgmental. It is possible that the Affordable Care Act may not in the end be revoked in its entirety. If it is to be revoked, it is at least conceivable that equal or better legislation could be introduced.

In view of this uncertainty, the committee decided it can do no more at this stage than monitor developments. If it seems that advocacy initiative is required,



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any such action will probably be in cooperation with other state and national organizations.

What we can be sure of is that the Coalition will always advocate for the best legislative environment for the treatment of very ill children.

## What do we know about grief?

A precis of a paper by John Waller PhD  
Associate Professor of History of Medicine, MSU

*Every year about 100,000 more American parents are left to grieve the loss of a child. As a medical historian, I have often reflected on the terrible rate of child mortality before the big epidemic killers retreated in the early 1900s, and wondered how people managed to get on with their lives after losing one or more child to disease.*

Such questions became excruciatingly personal when my son died of cancer in 2013. I realized that I, like most people, knew virtually nothing about grief. So what follows is a brief survey of recent research on the effects of child loss on the wellbeing of parents and the factors that might mitigate the pain of bereavement.

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### Grief and mental health

On average, parents suffer more after the death of a child than adults do after the loss of a spouse or parent. Although most parents do eventually resume the functions of a normal life – caring for other children, going to work, and interacting with friends – there often remains 'a perpetual state of bereavement' (Talbot, 1996; Hendrickson, 2009; Rosenberg et al., 2012; Rando, 1983). In Sweden, Ulrika Kreicbergs et al., (2004) compared bereaved and non-bereaved parents and found that 4-6 years following the death of their child the former had a 40% higher chance of anxiety and depression than the latter. In 2008 psychologists at the Universities of Georgia and Wisconsin identified bereaved parents from a database of 10,317 randomly selected high school graduates. Their dataset included 428 bereaved men and women with an average time since their child's death of 18.05 years. The study revealed that, although most of these parents were leading productive lives, in many cases the pain of their loss had barely diminished over the years (Rogers, et al., 2008).

Parental grief can be so debilitating that psychologists have proposed a new psychiatric diagnosis: Complicated Grief Disorder (CGD). They argue that CGD should be diagnosed if a parent is still experiencing low mood, regular and painful ruminations, the feeling that life is meaningless, and difficulty in resuming normal social and occupational functions six months after the loss of a loved one. For those who have lost a partner, 10-20% of the bereaved meet criteria of this definition between 6 and 11 months post-death. According to a 2011 study by Kathleen Meert (2011) of the Children's Hospital of Michigan in Detroit, when a child has died in a pediatric intensive care unit, complicated grief has an incidence at the six months mark of 59%. Maria McCarthy and colleagues (2010), at the Royal Children's Hospital in Melbourne Australia, found on the basis of self-reports that an average of 4.5 years after losing a child, more than 10% of parents were still suffering this form of extreme grief.

I suspect that many of us feel uncomfortable with redefining the devastating longing for our loved one as a medical disorder. When I think about how much I adored my son, no amount of sadness seems adequate. But the term 'Complicated Grief' is useful for two reasons. First, it draws attention to the fact that grief is not identical to clinical depression. Recent imaging studies suggest the involvement of a distinctive brain region associated with the expectation of reward. The intensely grieving become locked into a state of painful yearning because these expectations are never satisfied (O'Connor, 2008). Second, the concept of Complicated Grief provides a useful reminder for caregivers to look out for parents whose pain is unrelenting. As Karrie Hendrickson of Yale School of Nursing points out, the suicide risk of bereaved parents is a lot higher than that of the general population (Hendrickson, 2009; Murphy et al., 2003).



### The physical costs of child loss

Given the links between physical health and our subjective sense of wellbeing, it's not surprising that child loss can increase both morbidity and mortality. J. Li and his colleagues (2002) used the Danish national medical register to see if parents who had lost a child were more likely to die earlier. They found that between 7 and 17 years after the death, the bereaved were about 60% more likely to have a fatal heart attack than other Danes. Data from the Swedish National Health Registry covering child deaths between 1980 and 2002 tell a similar story: an increased mortality risk of 31% among mothers following the death of a minor child (Rostila et al., 2012).

Some of the most striking data concerns morbidity, especially levels of chronic disease (László, 2015). J. Li and colleagues (2004) demonstrated that Danish parents who'd lost a child had a 50% greater chance of devel-

oping multiple sclerosis after 8 years. Li suggests that psychological stress may sometimes play a role in the onset of MS. Another Scandinavian study, by J. Olsen (2005) revealed an almost 30% higher risk of hospitalization because of type 1 diabetes and a 44% higher risk for type 2. Olsen points out that stress has been implicated in both the onset of diabetes and in the deterioration of the condition in those who have it.

### Risk factors

A number of studies have looked to see what factors might increase the likelihood of parents developing complicated grief. It needs to be stressed, though, that we all grieve differently and so we can only talk about general patterns: probabilities not certainties. Consistent with this point, the relationship between the severity of grief and the cause of a child's death is less than clear. Some researchers, though by no means all, find that parents experience poorer physical health and a higher probability of psychiatric hospitalization if their child died in an accident or by suicide. A few studies also indicate that parents are at higher risk of anxiety and depression if they have less than 24 hours to intellectually prepare for the death (Rostila et al., 2011; Li, et al., 2003).

But having time to contemplate an impending loss is not always a protective factor. The parents of children who endured long periods of treatment before dying also report elevated rates of anxiety and depression (Jalmsell et al., 2011; Rando, 1983). A parent's perception of how much their child suffered seems to be very important. A survey of parents whose child died of cancer conducted at the Royal Children's Hospital in Melbourne revealed that complicated grief is most likely to ensue when mothers and fathers felt their child to have received inadequate end-of-life care (McCarthy et al., 2010).

The age of the child may be a significant factor in some cases. Hendrickson (2009) suggests that the suicide risk of bereaved parents may be higher when the deceased is between 1 and 6 years old at the time of death. Mortality rates in general are higher among mothers who have lost younger children (Rostila et al., 2012). There again, Rostila finds, the death of older children is also correlated with poor physical and psychological health.

A number of studies indicate that the characteristics of parents predict the likelihood of complicated grief. McCarthy et al., (2010) highlights the role of poverty in exacerbating the suffering of the bereaved. Social connectedness may also make a difference: Kreicbergs (2009) found that mothers and fathers gained from talking to friends, family members and other bereaved parents. Other research emphasizes the pre-existing psychology of parents. Elizabeth Lobb (2010) of Perth in Australia argues that severe grief is predicted by having a history of adverse events and insecure attachments and a negative worldview that leads to the avoidance of emotional problems. Similarly, Kathleen Meert finds that people who are anxious about attachments and are inclined to have a negative view of others are more prone to complicated grief.

Lobb, Meert, and a number of other authors, stress the value of being able to find meaning in life after a child's death. This might entail being able to assign meaning to the death itself or having other commitments that provide a renewed sense of purpose. The importance of maintaining a belief in the value of life perhaps explains why parents who have one or more surviving children are less likely to experience complicated grief (Keesee et al., 2008).

### Helping the bereaved

There is good evidence that social supports, financial wellbeing, and meaningful activities can mitigate the agonies of losing a child. Researchers have also tried to find out if psychotherapy helps (Shear, 2015). They have tended to conclude that for griever whose pain recedes enough for them to resume normal functioning (in spite of ongoing sadness), there are no obvious benefits (Currier et al., 2008; Mancini et al., 2012). There is, however, evidence that those suffering from more complicated forms of grief – those 'genuinely in need of help' – can benefit from psycho-

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*"What do we know about grief?" (Continued from page 2)*

therapy. But the type of psychotherapy appears to matter. A number of experts argue that the best kinds of intervention are tailored to the fact that grief is somewhat different from depression (Jabr, 2013). Although the bereaved may also have depressive symptoms, grief may require a more targeted approach. Katherine Shear and her team at the University of Pittsburgh School of Medicine have accordingly developed what they call 'Complicated Grief Treatment (CGT)' which involves having the bereaved repeatedly tell the story of the loss as well as developing future life goals (Shear et al., Simon, 2013).

Of particular relevance to the Coalition is the consistent finding that healthcare professionals can positively affect the course of a parent's grief. Survey data suggests that parents do a lot better after a child's death if: they had access to psychological support from the healthcare team during the child's illness, staff offered counseling on their own initiative during the child's last month of life, and they had the chance to discuss their child's condition during this final month. Accordingly, Kreicbergs et al., recommend that healthcare staff receive education on how to provide emotional support during the terminal stage of a child's illness.

In keeping with these findings, a Swedish study based on the results of a questionnaire concludes that many bereaved parents would value a personal follow-up meeting (Milberg, 2008). Ideally this would be with the staff member who had had the most contact with the patient and the family during the child's illness.

Research to date underscores a few key points: that true closure seldom comes after the death of a child; that the loss of a child can be psychologically and physiologically devastating; and that a subset of griever need professional assistance.

None of this should be read as implying that grief is unnatural. In fact, one might see it as the purest of all expressions of love.

**NOTE:**

*"What do we know about grief?" is a condensation of John Waller's original paper. The full text with notes and references will shortly be on the Coalition's web-site, [www.childpalliative.org](http://www.childpalliative.org)*

## 2016 Conference - Evaluations

*Though the 2016 Coalition Conference was well received, two attendees had a criticism – one pleading for more toilets (probably arising from misplaced signage), and the other for tissues (which we had, but not perhaps in the best location).*

From Evaluation report comments, both professional caregivers and parents appreciated the first speaker's disclosure of her personal experience. Pam Ressler RN (Stress Resources Inc., Massachusetts), attributed the years she spent caring for her son until his death as motivation to study stress relief. She learned that the isolation that follows bereavement also accentuates it, a vicious cycle that intensifies the pain. Social connection is important for both physical and mental health and for the bereaved it takes commitment to regain it. Her example of the Kintsugi bowl with its proud scarring in celebration of imperfection was a symbol that was significant to many.



Kintsugi bowl

John Waller's talk on the nature and broader impact of grief drew wide interest — reason enough to give him space (see opposite page) to set his thoughts on paper.

Jeff Lycan RN (Hospice Alliance of Ohio), also drew favorable comments on the topic, "Working together for change for the better".

Many appreciated his positive encouragement for the Coalition, coupled with his reminder to keep at it. His warning of not over extending while still needing to set clear goals was also well received.

The undisputed star of the program was the Parent Panel. "How courageous each member of the panel was to share their story", said one attendee. The stories and open emotion of the panel brought deeper meaning to pediatric palliative care.

The Parent Panel discussion was cause for the call for tissues. Facilitated by Jane Turner MD, eight parents participated and expressed their stories eloquently. The impact was powerful.

The day was also the inaugural meeting of the new Coalition. So the last item probably attracted least excitement – the business of the Coalition itself. That business (the only business) was the election of the Coalition board, and was accomplished speedily,



Parent Panel engages all

The nominees – Ken Pituch MD (University of Michigan/C.S. Mott Children's Hospital), Teri Turner RN (Anchors JoElyn Nyman Programs for Children), Bradd Hemker MD (Helen De Vos Children's Hospital), Jane Turner MD (Michigan State University), John Person JD (Hospice of Lansing), and Abigail Waller LMSW (Art for Charlie Foundation) – were elected unanimously.

The board elections were not in fact quite the last item of the day. A networking reception at a nearby pub (Dublin Square) had been arranged as a lighthearted addition to the agenda.

Those attending, however, suggested that networking opportunity should be an essential component for future conferences,

## 2017 Events

Friday to Sunday, May 19th to 21st — North Star Pediatric Palliative Care Family Camp — Pinckney, MI

Friday, November 10 — 2017 Pediatric Palliative Care Coalition Conference — East Lansing, MI

For updates on any event, contact organization directly or email [info@childpalliative.org](mailto:info@childpalliative.org)

# Committee Reports

(Below are summaries. Original versions and other reports can be accessed from the Members page at [www.childpalliative.org](http://www.childpalliative.org))

## Solace through Narrative Bereavement Report

The group discussed strategies to help families bereaved by the death of a child:

*Ensuring death of a child* is without fear of pain. A 'good death' can lessen the severity of grief.

*Ensuring that the relationship* between family and the medical professionals does not end at death. Families benefit from candid discussions with medical staff before the death and in the weeks after.

*Encouraging peer to peer support.* Parent members of the Coalition could be a core group to promote this.

*Enabling families to tell their child's story* since there is comfort in the telling. Pictures can provide a focus for the narrative – whether drawings by the deceased child or photographs.

Narrative outlets can be provided through the Coalition website, through exhibitions, and ultimately through books and other publications. The objective is to help bereaved parents and also to educate communities.

Hospitals can play a key role in advancing Committee objectives. They can help by putting families in touch with the Coalition after the death of a child, and also in helping the compilation of metadata by providing details of every child's death without disclosing identity. This data is key to assessing adequacy of available resources.

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## Redefining Fragile Infancy Perinatal Report

The committee amended their definition of "Perinatal" to 20 weeks or later, to distinguish perinatal care from "re-productive loss".

An early short term task will be to define "Perinatal Palliative Care" — what it is and what it is not — as a prerequisite for communicating to providers and the community.

Another key task is to compile a list of resources of perinatal support including groups that were diagnosis specific, or focused on pregnancy, education, inpatient-OB, outpatient followup, or on bereavement.

This would be with the objective of establishing a central repository to include resources, tool kits, examples of birth plans, also with reference to payers and location.

As this task progresses, the committee will need to explore ways to disseminate information about available resources to parents and providers.

In pursuit of this objective the committee might request help from the Michigan hospice and hospital associations and from members of Coalition to list providers of perinatal support in hospital settings.

An important longer term objective would be to define clinical best practice after prenatal diagnosis based on parent-driven evidence.

## 2017 Priorities Advocacy Report

As noted earlier, the committee considered the consequences of revocation of the Affordable Care Act, concluding that they would monitor events.

The committee evaluated issues to be addressed by the Coalition based on scores for impact and feasibility.

2017 priorities will include (1) defining and strengthening DNR ("Do Not Resuscitate") legislation in schools and other settings, (2) defining and widening criteria for reimbursement for doctors, nurses and other professionals providing palliative care, respite or bereavement services, (3) expanding concurrent care (already covered by Medicaid) to include commercial payers, and (4) improving patient access to care by telemedicine or assisted transport.

With groundwork on new DNR legislation by University of Michigan law students, this rated high on the scores for both feasibility and impact.

In promoting expansion of concurrent care, there are examples of successful lobbying by coalitions in other states, and indications that payers, though often opposed to it, save money.

The committee adopted Children's Special Health Care Services definition of palliative care that it "will enhance quality of life, and may also positively influence the course of illness."

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## Resources for Respite Respite report

The Committee defined "Respite" as "*Relief from the pressures of caregiving, regardless of where the caregiving takes place.*"

The Committee's mission is "*To be the clearinghouse on respite benefits for children with medically complex needs in Michigan and to share that information with healthcare providers, payers, and families statewide.*"

Objectives are:

- (1) to identify and assess resources available across the state and compile a guide,
- (2) define the need for and benefits of respite for children and their caregivers in order to advocate need and benefits to commercial and state payers, like insurers, Medicaid, and Children's Special Health Care Services,
- (3) to define the criteria for eligibility and the adequacy of current benefits or reimbursement, and
- (4) assess current models for respite to define best practices.

The committee is preparing a survey of current respite resources available to children and families. As a start, it will be sent to Family Support Services Coordinators at Community Mental Health.

Depending upon results obtained, the Committee may submit proposals to the Advocacy Committee for Advocacy or lobbying help.

## About the Coalition

The Children's Palliative Care Coalition of Michigan was registered as a 501(c)3 nonprofit corporation in May, 2016. While governed primarily by hospitals, hospices, and other institutions and medical practitioners who have a substantial focus on pediatric palliative care, associate membership is open to others who may be directly or indirectly interested.

More information on the Coalition's mission, membership and services can be found on the website.



**Children's Palliative Care Coalition of Michigan**

3032 Hamlet Circle, East Lansing, MI 48823

Email: [info@childpalliative.org](mailto:info@childpalliative.org) Phone: 517-763-4413

[www.childpalliative.org](http://www.childpalliative.org)