

Caring Connections

An Inter-Lutheran Journal for Practitioners and Teachers of Pastoral Care and Counseling



Pediatric Care and Consolation

The Purpose of Caring Connections

Caring Connections: An Inter-Lutheran Journal for Practitioners and Teachers of Pastoral Care and Counseling is written by and for Lutheran practitioners and educators in the fields of pastoral care, counseling, and education. Seeking to promote both breadth and depth of reflection on the theology and practice of ministry in the Lutheran tradition, *Caring Connections* intends to be academically informed, yet readable; solidly grounded in the practice of ministry; and theologically probing. *Caring Connections* seeks to reach a broad readership, including chaplains, pastoral counselors, seminary faculty and other teachers in academic settings, clinical educators, synod and district leaders, others in specialized ministries and — not least — concerned congregational pastors and laity.

Caring Connections also provides news and information about activities, events and opportunities of interest to diverse constituencies in specialized ministries.

Scholarships

When the Inter Lutheran Coordinating Committee disbanded a few years ago, the money from the “Give Something Back” Scholarship Fund was divided between the ELCA and the LCMS. The ELCA has retained the name “Give Something Back” for their fund, and the LCMS calls theirs “The SPM Scholarship Endowment Fund.” These endowments make a limited number of financial awards available to individuals seeking ecclesiastical endorsement and certification/credentialing in ministries of chaplaincy, pastoral counseling, and clinical education.

Applicants must:

- have completed one [1] unit of CPE.
- be rostered or eligible for active roster status in the ELCA or the LCMS.
- not already be receiving funds from either the ELCA or LCMS national offices.
- submit an application, along with a financial data form, for committee review.

Applicants must complete the Scholarship Application forms that are available from Judy Simonson [ELCA] or Joel Hempel [LCMS]. Consideration is given to scholarship requests after each application deadline. LCMS deadlines are April 1, July 1 and November 1, with awards generally made by the end of the month. ELCA deadline is December 31. Email items to Judith Simonson at jsimonson@aol.com and to Joel Hempel at Joel.Hempel@lcms.org.

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News, Announcements, Events: E-mail items to Judith Simonson at jsimonson@aol.com or Joel Hempel at Joel.Hempel@lcms.org

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Call for Articles

Caring Connections seeks to provide Lutheran Pastoral Care Providers the opportunity to share expertise and insight with the wider community. We want to invite anyone interested in writing an article to please contact one of the co-editors, Diane Greve at dkgreve@gmail.com or Lee Joesten at lee.joesten@gmail.com. Specifically, we invite articles for upcoming issues on the following themes:

2018, #1, “Ministry in the Time of Disaster”

2018 #2, “Joy in Ministry”

2018 #3, “The Opioid Epidemic and Addictions”

Have you dealt with any of these issues? Please consider writing an article for us. We sincerely want to hear from you! And, as always, if you haven’t already done so, we hope you will subscribe online to *Caring Connections*. Remember, subscription is free! By subscribing, you assure that you will receive prompt notification when each issue of the journal appears on the *Caring Connections* website. This also helps the editors and the editorial board to get a sense of how much interest is being generated by each issue. We are delighted that the numbers of those who check in is increasing with each new issue. Please visit www.lutherservices.org/newsletters#cc and click on “Click here to subscribe to the *Caring Connections Journal*.” to receive automatic notification of new issues.

Editorial

Diane Greve

SADLY, CHILDREN GET SICK. Sometimes they struggle for life in the womb. Sometimes they encounter death within their family and friendship circles that impacts their well-being. Sometimes they face behavioral health concerns at an early age.

Parents are their decision makers yet parents are emotionally entangled with the lives of their children, as they should be. And the parents have needs themselves that parallel their child's needs and are also distinct from them. How might chaplains, pastoral counselors, parish ministers, and healthcare providers best respond in service to these families in our care?

Both my children were born safely with little complication. Yet, I know the panic I felt when they needed hospitalization as children. However...being a grandmother of a granddaughter born 10 weeks early who needed to spend seven weeks in the NICU was a different matter. Through this experience I gained a window into what it is like for the grandparents as well. My heart went out to my daughter, her husband and their young son. We were all feeling helpless and confused. Should we feel happy because the baby was living or sad because her life was still uncertain. I will always remember that complex grief. Seven years later, I am grateful I can delight in this bright, energetic child.

In one day, I recently heard a mother share how much it meant to her to have members of the congregation sleep at her home, provide overnight feedings, and prepare meals after the birth of her baby that resulted in her severe post partem depression. And, the same day, I saw an article in the local paper about doulas coming into the home to help careworn parents adjust to a new baby. The faith community clearly is a resource for those who have such connection. My own young grandchildren had two close neighbors die in the prime of their lives along with two relatives, all within a few months. Prayers of the Church and the All Saint's Day remembrance was especially meaningful for them. Children grieve and some find comfort in ritual.

Pediatric care includes persons up to age 18 and sometimes beyond. It includes those who heal from their illnesses and return home as well as those who don't heal and/or return to their homes. It also includes critical mental health needs for children, teens and their families. Teenage depression and bi-polar disorder resulting in death by suicide is a major cause of death in the adolescent population.

Pediatric ministry is clearly a large topic for us to address in a limited space. Nevertheless, this issue provides a general overview and includes the thoughts and wisdom of parents, chaplains, a young adult, a physician/ethicist and a nurse practitioner.

- Brian Heller, recent graduate of Concordia Ft Wayne, offers insight drawing from his experience as a father whose baby needed to spend time in the NICU.
- Cheryl Plummer writes out of her personal understanding as a mother/chaplain who faced complicated pregnancies and describes how her discoveries informed her ministry. Cheryl initiated changes at one hospital as a result of her own experiences some years ago.
- Hal Weldin, a chaplain at Children’s Minnesota, identifies the challenges of parents in what he names the “pediatric burden.”
- Alexandra George, who has recently moved from adult chaplaincy to full time pediatrics, identifies some of the differences she experiences in serving the two populations.
- Kevin Powell, a pediatric physician and ethicist in St Louis, offers his wisdom in accompanying parents who are making life and death decisions for their children.
- BJ Larson, an ACPE Certified Educator, writes of her thoughts on how the faith community might be most aware of the signs of grief with children and teens. Allison, a young adult who experienced the support of her church during her most raw grief, speaks out of her memories as well.
- Kristen McKenzie, a PhD nurse practitioner in New York State, focuses her work on the mental health of children and teens. Her passion for collaborating with chaplains and local clergy in getting our children the care they need is much needed as we overcome the stigma of mental illness.
- Ghislaine Cotnoir has reviewed resources for serving this younger population when death enters their lives and thus becomes a factor in our ministry.

May the insights of our colleagues enrich our service with this critical population as we shape the next generations.

I ALSO WANT to thank Chuck Weinrich personally for his 10 years of faithful volunteer service as co-editor of *Caring Connections*. He has served with good humor and deep integrity. And I want to **welcome** Lee Joesten to the role of co-editor. His wisdom and thoughtfulness will serve our readership well. He will take the primary lead in the first issue of 2018. Both are amazing partners in this ongoing venture.

A Father's Lament from the NICU

Brian Heller

I CAN STILL HEAR those dreaded words like it was yesterday. “Your baby is being transferred to the NICU.” Something about blood sugar levels—I don’t know, everything was a blur. What I did know is that I would be returning to my wife from those so-called “routine tests” in the nursery without our first-born baby boy. That romanticized view my wife and I had, of holding our dear Isaac in the post-partum room as family and friends surrounded him, was shattered in a heartbeat. The magical birth we had been promised had taken a sharp left turn into what seemed an endless nightmare, and no one really seemed to know why.

Being in my fourth year of seminary, I had no shortage of pastoral support and care available. News about Isaac being in the Neo-natal Intensive Care Unit (NICU) spread around the seminary campus like wildfire. Phone call after phone call; visit after endless visit. Through my experience as a parent of a child in the NICU, there were three insights I came to realize about pastoral care that I would like to share with those ministering in that field. I hope I can follow them in my own ministry.

- 1. Timing is Everything:** There was one pastor we knew who prided himself in staying with families for an hour. As soon as I saw his number appear on my phone, I knew it was going to be a long visit—something I didn’t need or want. Sure enough, when he arrived, he made it his personal point to stay one full hour. He filled his time by interrogating me, “What is the blood sugar level at now? How much oxygen is Isaac receiving?” And the worst question he could ask, “When is he coming home?” Truth is, I don’t know the answer to most of your questions, and I’m asking them myself. Ask me a general question like, “How is your son doing?” That gives me freedom to answer your question as much or as little as I want. The visits I appreciated the most were from those that only stayed a few minutes to check in, asked how I was doing, assured me that they loved me and were there for me, and then left. Give me the power over how long you visit with me through generic questions. Don’t worry about staying too long or too little. By the tone of my responses, I’ll let you know.
- 2. It’s Not You, It’s Me:** No, really, it is. Don’t take personally the way I treat you. Remember where I’m at. I’ve only gotten 3 hours of sleep in the last 48 hours, I haven’t showered, and I haven’t eaten. I am grieving the idealized birth experience we had imagined. I am afraid for me son. Friends and family have been calling me non-stop, asking for the latest update. And, at this point, I can’t even *hold* my own son!

Ask me a general question like, “How is your son doing?” That gives me freedom to answer your question as much or as little as I want.

When you come in as a chaplain, talking to you may be the very last thing I want to do, especially if you're coming in during those sacred hours of peace and quiet. After 5 visitors had stopped by to care for us, the 6th one was greeted by a Brian I didn't even know. I was harsh, cold, and unfairly dismissive of him. I had nothing against this visitor, even considered him a friend, but the very last thing I wanted to do was talk to anyone. If I snap at you, talk back to you, or tell you to leave, please remember everything I am going through, and respect where I am at. Always know, though, that deep down, I appreciated you at least checking in on me, even if it may not seem like it.

- 3. I May Not Be Ok, But That's Ok:** One of the least helpful things for me in the NICU was when pastor after pastor would read those Bible passages where everything seemed to turn out OK. You know which ones I'm talking about... Jesus healing those lepers, Jesus healing the blind man at Bethsaida, being able to reach out and touch Jesus' cloak and be healed of just about anything. So, the visit would normally go like this: Jesus has done all of these great things; therefore, Jesus will care for you and your son as well. True, but not helpful. Right now, those miracles aren't my reality. Bethsaida is a 1000 miles away from me, and Jesus' cloak is nowhere to be found. Instead, I'm with Mary and Martha. Lazarus is sick, and Jesus is staying away from the NICU two more days. My son isn't getting better, and my prayers seem to be falling on deaf ears. I'm at a scary place myself and, if you could bring me out of my fear with a verse of assurance, I'd take it. But the reality is, those verses, as much as I believe their truth, will not help me in this moment. Instead, I want you to sit beside me. I want you to cry with me, be angry with me, and be scared with me. Let me cry out, "My God, my God, why have you forsaken me? Why are you so far from saving me, from the words of my groaning? Oh my God, I cry out by day and you do not answer..." (Ps. 22:1-2) Direct me to verses in the Bible like this. Take me to Job as he sits in the ashes to wait for the Lord after heartache upon heartache. Take me to the Jesus that cries over sickness and death. Take me to the reality that I am in, not the one where you want me to be. I need you to be ok with me not being ok.

I'm with Mary and Martha. Lazarus is sick, and Jesus is staying away from the NICU two more days. My son isn't getting better, and my prayers seem to be falling on deaf ears.

Ultimately, my time as a parent with a child in NICU was nothing short of horrific. Although we were only there for a week, it felt like an eternity. As you know, other families have to endure that nightmare for much longer—several weeks, even months. I give thanks to God for the outpouring of love and care He provided to my wife, son, and me through family, friends, ministers, and chaplains. Even though what you said and did may not have been as helpful as you would've liked,

you were showing me that you cared in the way you know best. That truly meant a lot to me. It really did.



A graduate of Concordia University Chicago (2011) and Concordia Theological Seminary (2016), Brian Heller has previously completed three units of CPE at Lutheran Hospital in Ft. Wayne, IN. During this time, he received extensive experience in ministering to a diverse group of people and situations. In the Spring of 2017, Brian received a call to serve within the Northern Illinois District of the Lutheran Church—Missouri Synod and currently serves as the sole pastor of Holy Trinity Lutheran Church in Walnut, IL. There, he resides with his wife, Jennette, and son, Isaac. Brian is also in the process of completing a fourth unit of CPE through an electronic extended unit designed and administered by Lutheran Senior Services in St. Louis, MO.

Tender Losses, Lasting Grief, Emerging Hope

Cheryl Plummer

SINCE WORKING IN HOSPITAL and hospice spiritual care, I have found that one often feels called to a ministry that is related to a significant life experience. I have always said that my ministry in the Antepartum (high risk pregnancy), Family Birth Center and Neonatal Intensive Care Units (NICU) found me after I went through two challenging high risk pregnancies, a devastating stillbirth and a very sad miscarriage. This was not an area of chaplaincy that previously had interested me but, after enduring these experiences, I felt I had a lot to offer to others facing similar times of crisis and loss.

Clinical Pastoral Education taught me that we need to heal from our own times of loss and grief before we can care for others who are suffering similar experiences. I also learned that one doesn't have to share one's own life events; rather, we can let them inform our ministry with others. I rarely told other mothers and families that I, too, was on bed rest, had two babies in the NICU, experienced having my son's twin die before birth or that I've had a miscarriage. Often I did draw on the feelings I had while going through these difficult times in my life to help me to better understand what other parents most likely were undergoing.

Yes, our high risk pregnancies, my time on pregnancy bed rest, my traumatic deliveries and our subsequent time in the Neonatal Intensive Care Unit with our babies were times of many ups and downs and so many varied forms of grief. It was also a time for potentially crucial, healing ministries to take place.

High Risk Pregnancies

Usually pregnancy is a time of joy, hope and preparation. When one has a high risk pregnancy it can be a time of anxiety, fear, guilt, isolation, boredom and hopelessness. There are so many things that physicians and literature and others tell us that we should be doing to have a smooth pregnancy and healthy baby. So when something goes wrong putting the pregnancy, baby and/or mother at risk, it is difficult for the pregnant mother not to feel she did something wrong. It also changes the perspective of the pregnancy and can cause the entire family to go into crisis when the pregnant head of the family is put out of commission.

When a mother is on bed rest is a time the faith community can help by providing pastoral visits, preparing meals, doing housework and helping to care for other children this family may have. Being linked to one's faith community can provide a very important source of both practical and spiritual support and comfort. As chaplains, an important role we may play, always with the patient's permission,

When something goes wrong putting the pregnancy, baby and/or mother are at risk, it is difficult for the pregnant mother not to feel she did something wrong.

is to help them connect to their faith community when they have one. In doing so, we may also help guide the patient's family and faith community leader as to what is helpful and not helpful for a patient going through a pregnancy crisis. Sometimes visitors are very much wanted and welcomed. And, sometimes they are not!

The patient and her spouse must be the ones to decide if they want their names on a congregational prayer list. Also, if the patient would prefer, the chaplain might suggest a statement be made during the announcements at their worshipping community as to whether or not visitors are welcome. This takes the pressure and stress off the expectant parents in dealing with unwanted visitors and gives them some agency in a situation where so much is out of their control. I have often encouraged patients to change their voicemail with updates and messages informing visitors of what they need. Wonderful internet sites are now available where patients and families can communicate with friends, faith community and family to send updates at one time so they don't have to receive numerous calls and explain their situation over and over.

For Christians, receiving sacraments during a pregnancy and baptizing the baby after the birth can provide spiritual healing and peace. Catholic families may ask for the Sacrament of the Sick. For those hospitalized mothers on bedrest, receiving Holy Communion reminds them of their continued place within the Body of Christ.

I would also offer a word of caution. I have had a few situations where patients have felt the sacrament was needed to heal their pregnancy or to keep them from going into preterm labor. In these instances we talked about the meaning of the sacrament, its purpose and promise. I explained that the sacrament is not a "magic potion" but an assurance of Christ's presence with us.

Sometimes an expectant mother can be on bed rest for many weeks or even months and, consequently, may miss important life events. Setting up live videos of family events they are missing such as a wedding, child's school event or even a funeral is not the same as being there in person. It is important for the mother on bed rest to be able to express her feelings and frustrations about these disappointments. Bringing part of the event to their bedside may be something for a chaplain to offer. I have arranged anniversary dinners, birthday parties, and even weddings at a patient's bedside. I have also shared religious rituals with patients on the antepartum unit. I have worked with more than one patient with a high risk pregnancy who have had to miss the funeral of a close loved one. When this has occurred, I have shared special and personal memorial services where the patients can share about their loved one and experience rituals that help them to say goodbye, facilitating their grieving.

Prayer is an essential part of all chaplaincy and there are many beautiful scripture passages, prayers and daily bible studies for pregnant women. I always

For those hospitalized mothers on bedrest, receiving Holy Communion reminds them of their continued place within the Body of Christ.

screen what materials are given to these patients experiencing a high risk pregnancy so it does not make them feel any additional guilt or loss since they are already grieving the loss of a normal, healthy pregnancy.

When working with families with high risk pregnancies there are three outcomes that may take place. One is the pregnancy goes to full term and parents take home a healthy baby after delivery; the second is that a baby or multiple babies are born prematurely and are admitted into the Neonatal Intensive Care Unit (NICU), and the third is there is the death of a baby or babies.

Neonatal Intensive Care

Ministry in the NICU is unlike ministry in any other part of the hospital. The patients are all small infants and the visitors are their parents. That, in itself, is an abnormal situation for a new parent. Plus, there is a great amount of grief and pain leaving one's baby at the hospital. Then, the parents have to leave them day after day until they hopefully come home, sometimes weeks or months after their birth. Ask any mother who has had a baby in the NICU and she can tell you her child's birth date and the date they finally came home from the hospital. That day of celebration can be acknowledged by the chaplain with a prayerful sending ceremony for baby, family and staff.

New parents in the NICU have to face the reality of allowing someone else, physicians and nurses, to make decisions and provide a lot of the direct care for their child. Sometimes it can be days or weeks before the parents of a preterm baby can even hold them in their arms. They also have to cope with the joy of giving birth alongside the pain of having a very sick baby who may be unable to breathe or eat on their own. Spiritual comfort and supportive rituals are an essential part of ministry in the NICU. Sometimes, we as chaplains can give the parents the gift of helping them to feel like parents even though so much of the care of their new baby may be out of their control in the beginning of their child's life.

Often preterm newborns are baptized at the time of their birth, sometimes right in the delivery room or right after birth in the NICU. If a baby does receive an emergency baptism in the hospital, it is another rite of passage and important ritual that these parents are experiencing in an abnormal, hurried way. When working as a chaplain in this area, I kept in close communication with family and clergy of these families so baptisms could be recorded in church records. Also a service acknowledging the previous baptism can be held at the patient's faith community with a baptismal gown and with church members, family and friends present. It can be a perfect time to present a baby to a church who has been praying for this infant and the family.

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Infant Loss

Probably the most important ministry in mother baby care units takes place when there is a perinatal loss. Miscarriages, stillbirths and infant deaths are such a crucial time of spiritual need. It is a loss of a family's future, hopes and dreams. These parents have just a moment to say hello, and at the same time, have to say goodbye to their precious child.

Here is another instance when the sacrament of baptism becomes a critical part of ministry. I have participated in many theological debates about whether or not to baptize a baby who was stillborn or who died shortly after birth. Lutheran theology tells us that sacraments are for the living, a way to unite us with the death and resurrection of Christ and with the Christian community. Logic tells us that once someone has died they are no longer in need of sacraments, they are with God. Having said that, when a mother and/or father experience the traumatic loss of the death of their baby, they sometimes have a deep desire to have their baby baptized. Some of the grieving parents have expressed that providing this sacrament for their baby helps them to feel that they are placing their child in God's arms. It is a personal choice, but as a chaplain, I have never refused this request from a grieving parent and, at their request, have always baptized their babies whether they are living or deceased. I have witnessed situations where pastors or priests are unwilling to baptize a baby born dead and I have seen it separate these parents from their faith communities, sometimes forever. When churches do not acknowledge these deaths like they do the death of an older child or adult, they can cause an unrepairable rift between a family and the faith community. It can make or break their relationship with the Church. Memorial services, funerals and other rituals can provide the grieving parents, aunts, uncles, siblings, grandparents and family friends with the blessed assurance they crave at this tender time. As chaplains we can suggest ways for these religious needs to be met.

I have participated in many theological debates about whether or not to baptize a baby who was stillborn or who died shortly after birth.

Personal experience informs new programming

As I said in the start of this article, our personal experiences can lead us to be a part of certain type of ministry or chaplaincy. This was very true for me. We had some very painful experiences when we went through our miscarriage and the stillbirth of our son's twin. We did not receive enough information and options to give us the needed support and comfort when our babies died. We were rushed and pressured into decisions related to the final arrangements for our stillborn son, decisions that we later regretted. We were also left with very little memorabilia for a baby who was delivered far enough into his gestation to have possibly survived like his twin did.

Our experience led me to join a group at our health system that developed a more evolved and compassionate Perinatal Loss Program. With funds from the foundation of our health system we made an arrangement with a local crematorium that allowed us to offer free cremation for babies who died due to miscarriage, stillbirth or newborn death (death prior to ever leaving the hospital). Then we built our own columbarium at a local cemetery so the ashes of the babies could be interred at no charge to the families.

We located specialists to provide training for staff from all of the Maternal Child Health units involved with perinatal loss. For these days of training we had authors knowledgeable on this subject and an agency who prepares hospital staff to respond compassionately to this type of grief. In addition, we had a parent panel, of which I was a part, who shared our experiences, positive and negative, related to care we received after our babies died.

Prior to this time, our hospital took one or two, sometimes blurry, instamatic photographs of the deceased babies. Now, with permission of the families, we take more professional photographs of the babies. The parents of deceased babies may take the photos right away, but if they want to think about it, we keep them for six months. While these photos can be painful for some parents to see, these are the only photographs they will ever have of these precious little ones. Many families want photos of themselves holding their babies.

We contracted with a local artist to make special memory boxes for the families. Mementos one usually gets when a baby is born such as baby bracelets, ink footprints and a card with information about the baby's birth are placed in the memory box. Spiritual Care had special cards designed to commemorate baptisms that have taken place at the hospital. We have supplies to make three dimensional plaster casts of the baby's hands and feet. We have donated clothes and baby blankets. When a family is ready, a nurse, social worker or chaplain, preferably someone who has interacted meaningfully with the parents, will take the baby to the morgue. The blanket in which the baby was wrapped is left with the parents. A book about how to cope with this death and other written resources are also provided to the family.

We have developed perinatal loss support groups and we have a yearly multi-faith memorial service at the chapel in the cemetery where some of the baby's ashes are interred. We have worked with several local funeral homes to help these young families, who are often unprepared to make final arrangements, so they can receive lowered costs if they chose burial versus our free cremation option. Most funeral homes will help a young family who has had a baby die, and do not have the financial resources available to provide their baby with the funeral and burial they desire.

We have developed perinatal loss support groups and we have a yearly multi-faith memorial service at the chapel in the cemetery where some of the baby's ashes are interred.

An important aspect in helping a couple whose baby has died is preparing them for their time after they leave the hospital. Everyone grieves in different ways and this is true of a couple who have experienced a perinatal loss. The mother, who has given birth to the deceased baby, frequently is home for many weeks recovering from the delivery while her spouse or significant other has to return to work. This leaves a new mother at home, physically healing, but without their precious baby. As chaplains, we can help prepare these patients for what to expect when they go home and provide them with resources if they need help coping with their grief. Our pediatric hospice has started working with families who have had a perinatal loss to provide them with ongoing bereavement counseling once they have left the hospital.

In perinatal loss we as chaplains have one of the most important roles. We can provide naming rituals and bedside memorial services that are so meaningful and essential for beginning the grieving process. These bedside rituals are sometimes even more important if a family has chosen cremation. While working in this ministry, I always kept a baptism in emergency service and a brief service for miscarriage, stillbirth and infant death in my possession.

One of the things I found most helpful as a parent and as a maternal child health chaplain who had two babies die was when chaplains and others took the time to acknowledge this painful loss. When someone acknowledged that, even though these babies are in heaven, they are still a part of us. They are members of our families and we are still their parents. And, they are not forgotten.



Deacon Cheryl Plummer received her BA degrees in theology and psychology from Valparaiso University. She is a consecrated deaconess of the LDA in Valparaiso, Indiana, and is a rostered Word and Service minister with the SE Michigan Synod of the ELCA. In recent years Cheryl has done graduate theological studies through the Ecumenical Theological Seminary in Detroit. She has been a chaplain for Beaumont Health System in Detroit for over 29 years and has specialized in Trauma, Oncology, Maternal Child Health and Pediatrics. For the past 13 years Cheryl has worked for Beaumont Hospice. She likes to travel and spend time with her husband, their four children and two grandchildren.

The Pediatric Burden

Hal C. Weldin

PEOPLE CHOOSE to work in pediatric settings because they love children. This love for kids is the common thread in a hospital setting that connects Spiritual Care to nursing, doctors, social workers, the maintenance crew, and basically everyone that works in the hospital. We are employed by the hospital and paid for our services for sure, but what drives us is our desire to make a positive difference in the lives of children and their families. Not everyone in the hospital gets to work directly with the patients we serve. However, no matter what our discipline and role in the hospital, what binds us all together is our care for the well-being of children and our desire to give them the care they need to heal, grow and thrive. There is something remarkably right and good to be a part of a large and diverse team that cares for children. And we rejoice with those who are able to return to their homes and families where they can live life for as long as they are able.

The burden for us is that some children don't get better under our care. Sometimes they come to us because they have been in an accident and their little bodies are too injured to recover. Some little ones are born with bodies that have complex challenges and they live for a very short time. And it doesn't take long for anyone working in a pediatric hospital to learn a very hard lesson about our world. Some children get sick, really sick and some die. It's hard to even type that phrase, because this is not how the world should work. Kids should recover from any illness, grow up strong, and outlive their parents. That's how the world "should" work. But, those of us who work in pediatric care know and carry a different reality. As Chaplains, we come alongside these children and their loving families and enter into their suffering, their disenfranchisement with life and their crushed expectation of the way things should be. That's what pediatric Chaplains do every day. Because our beloved children do get horrible diseases that their little bodies cannot fight off or sometimes they are victims of terrible accidents that result in a very short time of life on this earth, we are there for them.

I call it the "pediatric burden." It's one thing when Grandma at age 95 is dying and is moved into hospice care. She's lived a good long life and made lots of memories. Someone who has lived for 95 years has had opportunity for a full life experience and maybe even has the privilege to prepare for their death by getting things in order and having closing conversations.

It's quite a different thing when a 5 year old, who has been fighting a stubborn brain tumor for three of their five years on earth and now comes back into our care

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because of yet another relapse. Now the child and family must face that there are no treatments left to cure. A heaviness fills the hearts of everyone involved. In this situation, the palliative care team appropriately meets with the family and offers a comfort plan of care. The air is sucked out of the room. All the adults in the room feel an inner pain that a child is dying on our watch. That the adults in our human culture are responsible to protect and care for the children is something so basic, even ancient, in its origins. We all feel this responsibility as some whispered inner response that tells us, “this should not be happening; there must be something we can do.”

This pediatric burden is expressed by parents and other loving adults in additional ways. Many times the father or mother will say something like, “I wish there were some way that I could take my child’s place, that it were me in the bed and my son/daughter sitting in my chair. I’ve already had many years of life and my child’s life is just starting.” Deep within a parent’s heart is a love that yearns to take the cancer, the injury, the pain, and the suffering upon themselves. This type of intense grief and struggle can morph into anger, sadness, sleeplessness, and bitterness. One such parent who wished they could take their child’s place stated it this way, “Chaplain, if this is how life is, I no longer trust life itself.”

The future they had imagined and hopes they carried before these events seems to be no longer relevant.

Then we struggle with words. For some in this situations, there are no words, there is only disillusion and pain. It is as though everything in this child’s family’s life has been placed on a spinning top. For some families, they lose their future hope when they receive a new diagnosis. For others it happens when the curative treatments fail; for still others it is the moment of their child’s death. The future they had imagined and hopes they carried before these events seems to be no longer relevant. Those past hopes and dreams seem very far away or even like they never really existed. The family then starts the long grieving process to reassemble some kind of future hope that will integrate this new and unwanted life event of losing a child.

What can we do to provide compassionate care as Chaplains for these families struggling with this pediatric burden? The answer is of course different for each family. Some need respectful space to find their own way, so we come along side to remind them that we are here if they want to talk. Others feel like they have lost their faith as they are losing a child. Some become mad at God for not intervening and allowing an illness or injury to affect their beloved child, so they want nothing to do with a Chaplain or Spiritual Care. Still others feel the weight of their anticipated loss and simply need to protest while they struggle to keep themselves together and present.

With all families we can remind them that they are not alone, because we know for sure that isolation makes everything far worse. We can encourage them to find

the one or two people in their support system that loves them and can be with them when they are in pain. As Chaplains we can offer a listening, caring space for family members to explore their feelings, their burden and that part of their lives and belief system that matters most. Listening and creating safe places to explore their way forward together is the bread and butter of pediatric Spiritual Care.

For those families with a Christian faith, we can remind them that God is not afraid of their protest or anger. Our scripture is full of people God loves that shake a fist, run away, deny, and protest. One scripture I often use is the dialogue between Jesus and his disciples in John 14. Thomas says in verse 5, “Lord, we do not know where you are going. How do we know the way?” (If they know their scripture, I ask them not to skip forward to John 14:6. But to stay with Thomas’s question.) I wonder with families if this might be their prayer? “God we don’t know what you are up to or where you are leading. We need your direction and in this moment feel so lost.” Rather than pretending he understands the words of Jesus, Thomas had the courage to state that he does not understand or even know the direction forward. It is ok to feel spun around, angry, and even lost. God welcomes the real you, struggle and doubts all mixed together with pain. God not only can take it, but you as a faithful Christian do not need to pretend it’s all right. It is a faithful act to struggle and admit that you don’t know how to go forward. Like Peter, Job, Moses, Paul, and a host of others in our scripture, deep protest, struggle and doubt can be a part of our faithful story too.

God welcomes the real you, struggle and doubts all mixed together with pain. God not only can take it, but you as a faithful Christian do not need to pretend it’s all right.

I’m learning that as a Chaplain, we hold a unique position in lives of the families we serve. In some ways, family members can be completely honest with us, because we are outside of their faith circles. They can wonder, doubt, deny, confess and struggle with us in their moment of need without worrying about their own reputation or ability to keep the faith. Kids, parents and grandparents can explore their questions and doubts with us without the concern that some may have that if they were struggling openly with their own faith leaders or community, they may risk having them think less of them because of their struggle. There is a freedom we offer to them because we are not a part of their faith history. Part of caring for their spirits is to hold a safe space where they can do the hard work of examining their beliefs in light of their current life experience. In some ways we are like the medical specialist, who comes in for a specific service that involves a short period of time. We are not their Primary Physicians. Chaplains step into a critical moment of intensity, all the while knowing that our interaction is inherently not on-going, but short term. We do not become their faith leaders; rather we seek to further support and integrate them back into their own faith community with their own faith leaders that hopefully will be with the family for the long run.

It is a sacred privilege to do this work of caring for children and family in a pediatric setting. We are invited into people's lives when they are discovering that their whole world view and future hope is being rearranged to include the experience of a pediatric burden. As painful as these moments and human spaces can be for us to co-inhabit, we also experience the deep meaning that comes from being a voice of compassion and care in our families' times of greatest need.



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This Little Light

M. Alexandra George

A Brief Introduction

I was pleased to be invited to write for *Caring Connections* about my experience as a chaplain in adult care and about my transition to working with children. It is rare for me to take a moment to reflect on a transition. I was content in my position at an adult Level II hospital in the Minneapolis area, but within a few years I felt drawn to work with a younger population. After seeing the St Paul Children's Hospital posting I applied and interviewed and was invited to join the Children's Minnesota staff. I knew that working with children and families was going to be different from what I had known. In on-call work I saw a few families per month for a moment in time without follow up. In my new position as a full-time chaplain, I was going to be immersed in intense experiences every day. When I walked in the door for my first day of work I knew that Children's was the right place for me.

The environment at Children's is healing. The areas where families gather at Children's are created to stimulate a child's imagination. Adults benefit too! One of my favorite areas is the star hallway that connects two buildings on the campus. The entire length of the wall is filled with very large stars that, when pressed, make familiar animal sounds. It is delightful to watch children discover the wall for the first time. On my more difficult days I make sure to press a star of a pig grunting which makes me smile and releases tension from being part of a difficult case. I don't know what it means theologically to press a star and hear an animal sound, but I know that it grounds me spiritually on those rough days when there are many intense cases.

Throughout their struggles the one thing in common is that most patients had a strong desire to keep their light shining in this world.

This Little Light

When I began writing this reflection, a well-known spiritual came to mind: *This little light of mine, I'm gonna let it shine. Let it shine, let it shine, let it shine.* This spiritual is about the light that each person has in this life. Our light shines in the good times and in dark times. It is our own unique life experience that shines.

In my 10+ years as a chaplain I have met many shining lights in hospital visits with patients and families. I had the honor of walking with adults and children through struggles with disease, illness and physical pain. Throughout their struggles the one thing in common is that most patients had a strong desire to keep their light shining in this world. They fought for life and many times won.

I will never forget an adult patient I visited that had a severe case of diabetes. He lost two limbs and was in the hospital for an assessment. Throughout most of the visit this patient told jokes, he made everyone laugh with him, and he was pretty funny. Under all of that there was suffering. He no longer had legs and soon he might lose an arm. In a brief serious moment, the patient shared with me that this has been tough for his family. He knew that if he became sad and depressed, it would serve no purpose. His faith helped him make a conscious decision to approach life with lightness and with humor. His light continued to shine long after he was discharged home.

With adult patients it is easier to talk about what is going on for them. Patients are often willing to process and find words for their experience with their illness. They will talk about family, friends, faith, meaning in life. The chaplain can know first-hand what the patient is feeling and thinking.

It is much harder to know what children are thinking. In my first few months at Children's I became involved in care for an infant with spinal muscular atrophy (SMA). The child could not be moved or held, and had to remain on his back due to his disease. He learned to speak with his eyes. He would look and sometimes smile which meant he was pleased or maybe that he recognized you. He smiled with his eyes. When the child was ready to be discharged staff sent him off with a grand farewell. Everyone loved the light that this child brought to the unit.

I will tell parents that it is their job to hope, and I encourage them to do those things that help sustain them in their hope and to stay connected with their child.

Parents I have worked with live in hope and they want everything done to help their child live. I will tell parents that it is their job to hope, and I encourage them to do those things that help sustain them in their hope and to stay connected with their child.

Children try so hard to keep their light shining during a lengthy illness. Most often children are not able to talk or process their struggles. Infants will never be able to tell you that they are hurting or when to stop all cares. They communicate everything with their body and their emotions. Their struggles with lines and medications are sometimes the only way of keeping their light shining.

It is difficult when the medical staff tries everything possible and yet nothing seems to work. It is like the one birthday candle on the cake that lights for a brief time and then goes out. After a few attempts to keep the candle lit, it stays out. This is how it can be with children. This bittersweet pill I had to learn to swallow was, like the parents, you believe that a medical intervention should work. Yet, no matter how hard we try, the treatment does not always produce the desired result.

The Light No Longer Shines

I was asked to see a child that was born healthy and, at around 24 months, she started to decline. She had been walking and now was not able to walk or even stand.

She was previously speaking but now her speech was reduced to a few words. This was hard for me to understand. What happened to this child?

I learned that she had a rare degenerative disease that would worsen and end in death. I made a connection with the parents and grandparents and at their request baptized their child. The child was kept comfortable and eventually went home on hospice. She continued to decline and then died within six months of her diagnosis.

This was just one example of how my theology is stretched and tested on a daily basis at Children's. I had many questions, but there were no answers. My faith tells me that God is present and that may have to be enough. At times like this, the interdisciplinary team becomes a primary resource for support. I connected with our interdisciplinary team to process this challenging experience.

Interdisciplinary teams are an important part of our work at Children's. Spiritual Care, Social Work and Child Life often work together, especially in difficult cases. We complement each other and tag team so that we can remain fresh in our care giving. This intense team work was new for me and I welcomed this additional support.

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In adult hospitals I have often been the only psycho-social team member present at a death. For an expected death, Spiritual Care provided the psycho-social presence for the family. If the adult patient was in an accident or had a sudden unexpected death I would work with the interdisciplinary team to provide bereavement care. In an ER death I had more involvement with the Medical Examiner and would support the family during this process.

One thing I miss is the intimacy of working with adult patients at the end of life. They tend to be more concerned about forgiveness and reconciliation. Adult patients clearly demonstrate Ira Byock's *Four Things that Matter Most*: "Please forgive me," "I forgive you," "Thank you" and "I Love you" through their actions and interactions with others. Often the rites at the end of life will involve baptism or communion. The conversations and rituals have a spiritual dimension for the patient, family and the chaplain. The room is transformed into a sacred space.

Working with children at the end of life is one of the most challenging experiences because emotions are so intensified. Children do not have much history. The pain of a short-lived life will last a lifetime for parents and families. They hold on to the memory of their child through keepsakes—a lock of hair, foot and hand prints, etc. They want anything that can bring them closer to the moment when their child was alive. For me, this is the toughest part of working with children and families. It is surprising that it is more difficult to maintain a sacred space when a child dies. The room is often busy with staff and family members coming and going. I will often ask for a moment alone with the family and check in with them about they want to spend time with their child, so that they can have some control over their last moment.

Conclusion

A hospital is often a place of healing and where hopes are fulfilled. Yet, sometimes it is a place to let go of dreams. Being a chaplain for adults and children in these spaces is difficult and rewarding. The common thread in all of my life transitions has been my faith. When I tell people that I am a chaplain at Children's it is too frequently followed by a sad facial expression and the words, "that must be a hard job." Yes it is a hard job and many tears are shed. It is also a call that deepens my trust in a God that is present and at work in the world in the middle of crisis and trauma. I will keep moving on the path, shining my own light, so that *together* we can light the path for ourselves and for those we serve.



Rev. M. Alexandra George was ordained as a Lutheran (ELCA) pastor in 1999. She served at Zion Lutheran Church in Minneapolis and at the church's non-profit ZOOM House. She followed her passion for chaplaincy and began her residency at United Hospital, St. Paul, MN in 2005. After completing her training, George worked on-call and part-time at Twin Cities hospitals, including pediatric settings. George became a staff chaplain at Mercy Hospital in 2012 and was Board Certified by the Association of Professional Chaplains in 2013. In 2015 she accepted a full time pediatric chaplain at Children's Minnesota, St. Paul campus.

Caring for Chronically Ill Children and Their Families

Kevin Powell

MODERN MEDICAL SCIENCE continues to produce amazing advances in technology. These advances have rescued many lives and significantly improved life expectancy. They provide alternatives that enable children with disabilities to participate more fully in the community. With these blessings have come great financial and emotional costs to the caretakers, families, society, and health care professionals.

All this scientific progress challenges theology and pastoral care to keep pace. The issues can be grouped into three major impacts. First, parents are confronted with choices they did not have in the past, such as stopping life support. With those choices come stress and guilt, even when death is imminent and inevitable. Pastoral care can help parents clarify values and reach decisions when the parents have no paradigm or role model to guide them on what it means to be a good parent under such circumstances.

The second major impact is on stewardship of resources. Americans spend far more money per capita on health care than anyone else in the world. New technology aggravates this issue. Jesus cured a blind man using dirt mixed with spittle. A new gene therapy approved in 2017 will improve a rare genetic blindness for \$700,000. Modern sermons on stewardship must be more socially relevant than yearly pledge drives or recommending composting on Earth Day.

The third impact is the moral distress of the medical caretakers, including nurses, therapists, physicians, and family members of the patient. There are times in end of life care when the medical team perceives further treatment as futile and as only prolonging suffering of the child. This contributes to professional burnout and cynicism.

The case of Charlie Gard

In the vast majority of cases, medical care decisions are made by parents in consultation with their physicians. In situations of conflict, second opinions can be obtained. Ethics committees and chaplains can facilitate values clarification, provide moral guidance and mediate. The legal system is usually too slow, burdensome, and unpredictable to be used except as a last resort.

Last summer one case in London, England did end up in court. It involved an infant boy named Charlie Gard who was born with a very rare genetic disorder that causes severe muscle loss, seizures, brain damage, and death in infancy. As his

Jesus cured a blind man using dirt mixed with spittle. A new gene therapy approved in 2017 will improve a rare genetic blindness for \$700,000.

condition deteriorated, his parents wanted to try an experimental treatment at a New York hospital. They even obtained over one million dollars in crowdfunding to pay for the travel and treatment. The medical staff at the London hospital disagreed. The treatment had never been tried on someone with his particular genetic variant, so the likelihood of success was low and unproven. Charlie had already endured permanent brain damage that would not be reversed by the experimental treatment. Nurses were concerned that continued medical care was causing Charlie to suffer. The medical staff advocated stopping mechanical life support and allowing Charlie to die naturally.

It is rare for cases like this to end up in court and even rarer for judges to rule against rational, articulate parents. But the English family court assessed what was best for Charlie and concurred with the medical team's recommendation. After the parents lost in 2 appellate courts, the European Court of Human Rights reviewed the situation and declined to hear a third appeal. Charlie's health worsened and by July 2017 the consensus was that the experimental treatment could no longer be of benefit. Life support was withdrawn and Charlie died in a hospice a week before his first birthday.

Parents do not own children. Parents have authority because they are presumed to be best suited for making decisions in the best interests of their child. If medical staff disagree with this presumption and cannot negotiate a compromise, then the medical staff must report the case to Child Protective Services. The child is appointed a guardian to advocate for the child's interests during legal proceedings. The child's best interests are the paramount consideration in court.

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Baby Joseph Maraachli

The case of Charlie Gard in the British and European courts has many parallels to the case of a Canadian baby in 2011. Baby Joseph had a metabolic brain disease that caused a coma and dependence on a ventilator. The parents wanted a tracheostomy in hopes that it would prolong Baby Joseph's life and allow for him to be cared for at home. The medical staff at the hospital concluded that such care was not appropriate. The Ontario Consent and Capacity Board determined that the child's best interests were to have the breathing tube removed and the child be allowed to die peacefully. The Board ordered the parents to consent to this and the parents refused. Ultimately, the child was flown to a Catholic hospital in the United States. The doctors there assessed the child. They did perform a tracheostomy, which is a more stable airway for a ventilator used at home. The baby then returned to his home (not the hospital) in Canada, remained in a coma, and died six months later. The father, a Muslim,

expressed the belief that by obtaining the tracheostomy he had fulfilled his duty to his child as God had called him to do.

Doing everything

These two cases, 6 years apart, are exceptional cases that, by their rarity, reveal that in most cases parents and medical staff reach a consensus on what is in the best interests of the child without courts. Most palliative care physicians and clinical ethicists would say that modern American medicine too frequently errs on the side of continuing futile, aggressive treatment, even when it only causes pain and suffering with no realistic hope of cure or improvement.

The typical lay person is rarely confronted with issues of stopping aggressive treatment and shifting to comfort care. Most cases involve terminally ill elderly patients and the decision is foisted upon a spouse or adult child. Faced with devastating news that their child is dying, parents need first to cope with the emotional and spiritual shock. This takes time and support.

The stories in the Bible come from a time when health, life and death were considered out of human control and in God's hands. Disease in the Bible is often attributed to fate, God's Will, and as a punishment for sins. This imagery (mis)informs the congregation and contradicts science. Pastors, trained in hermeneutics, need to provide a more nuanced interpretation, preferably before a crisis situation occurs. Acceding to the death of their child is nearly inconceivable to any parent who has not provided months and years of care to a chronically ill child. In my experience as a pediatrician, once a loving parent has concluded enough is enough, I have always been in agreement.

The typical lay person is rarely confronted with issues of stopping aggressive treatment and shifting to comfort care.

At some point, parents will generate a narrative. A common paradigm is to label chronically ill children who survive as heroic "fighters." Parents, struggling to cope without role models about what it means to be a "good parent" in these tragic situations, often adopt a strategy of "doing everything" for their child. The parent hopes and prays for a miracle. They frame the situation as a test of faith. They feel they must not give up hope if they are to be worthy of that miracle. This paradigm of doing everything can be a maladaptive. It may be futile. It may unnecessarily prolong suffering. It is also false reassurance, since in retrospect a parent can always think of more things that might have been done.

Catholic theology is well-developed on the differences between ordinary and extraordinary care, as well as the doctrine of double effect. The Lutheran Church—Missouri Synod publication "Christian Care at Life's End (1993)" adopted a similar theological understanding. There have been recent changes in conservative Catholic theology. Pope John Paul II's allocution in March 2004 indicated that artificial

hydration and nutrition is ordinary care that should not routinely be withheld. The more liberal medical ethicists in many Christian denominations do not agree with this trend and consider artificial hydration and nutrition to be medical care that can be appropriately and legally refused by a patient or a surrogate.

Find a different narrative

To avoid false theology and dysfunctional behavior, the parents will need to hear and adopt a different narrative of what it means to be loving parents to a dying child. They need to find joy in the time they have left. They need to come to terms with guilt and anger. Pastoral care involves correcting naïve theology. It involves giving a parent (and other family members, especially young siblings who can't express their feelings) permission to feel angry, to express doubts, and to grieve what has been lost even before the child has died. It means helping the parents articulate and critique their narrative.

They need to find joy in the time they have left. They need to come to terms with guilt and anger.

Many marriages become all about caring for the chronically ill child. Divorce is common after the child dies. Parents have grown apart from each other. Pastors can remind parents that marriages take work and that they must find time for their own relationship. Arrange date nights when the child is in the hospital. Have congregational members provide respite care for even a few hours. An occasional good night's sleep does wonders for a caretaker's capacity to provide care.

Stewardship

Modern health care is expensive, but trying to deal with this issue at the bedside of an individual patient is almost never productive. Resource allocation needs to occur at a higher level. It is now truly possible, on average, for money to buy health. The expansion of Medicaid under the Affordable Care Act has improved access to health care over the past seven years. However, it remains to be seen whether the improvements in health from that access are overshadowed by the burden of the increased national debt. Health is heavily impacted by socioeconomic determinants. These include family income, job security, food insecurity, education, housing, social exclusion, and addiction. Those are issues that congregations can address.

Scientists working on medical advances need to consider the impact of their work. Why, after 30 years of research on the AIDS epidemic, do we have expensive treatments that control the disease, but no cure and no vaccine?

Another example is the Back to Sleep program in 1994, which reduced SIDS (sudden infant death syndrome) by half. The simple act of laying young infants to sleep on their backs saves more lives each year than pediatric heart and lung transplants. But researchers can't identify which babies were helped. Public health programs don't garner as much prestige and publicity as snazzy treatments that help

a particular, identifiable patient. Idolatry, pride and vanity can distort goals. Adult education in churches helps to reinforce a scientist's moral compass.

Moral Distress

There are times when the treatments demanded by a family may seem only to prolong suffering of the child. This is particularly hard on nurses who are at bedside for hours at a time. One script for health care workers has been dedication to the point of a misguided martyrdom. It isn't healthy for patients or staff. The false path of justification by works is particularly well refuted by Lutheran theology. Suicide, burnout, and divorce are too common among health care workers. This has recently become a focus of health care organizations. There is now acknowledgment that caring for oneself is a professional obligation. Nurturing the soul has long been a major function of religion. Some practical, pastoral counseling is also needed.

Working as teams puts pressures on some staff to do things with which they personally disagree. It is another form of moral distress. Some policy makers prize efficiency and equity. They advocate treating medical professionals as automatons who must obediently perform tasks they are trained to do, rather than recognizing persons as moral agents within a vocation. A personalized religion, such as Lutheranism, must oppose such depersonalization by advocating, where appropriate, for accommodating conscientious objection, doubts, and individual understandings of what God calls people to do. It is a messier social contract, but preserves humanity.

Futile treatments are a major source of moral distress in intensive care units. Futile treatments may briefly prolong existence but they do not benefit the patient or society. Imagery of the infinite value of life needs to be balanced with the perspectives of idolatry, mortality and, for Christians, salvation.

Imagery of the infinite value of life needs to be balanced with the perspectives of idolatry, mortality and, for Christians, salvation.

Postscript

Cases like Charlie Gard will never be easy, but sometimes saying no to a parent will be the greater kindness.

These cases are at the intersection of technology, medicine, ethics, and compassion. Input from only one of these fields is inadequate. Wisdom is generated at the blurry interfaces between them. The pews are a place where people from these different fields could interact, if congregations were better at welcoming scientists. Too many scientists leave their science vocation on the steps as they enter the church. That weakens their ability to inform community stewardship and calibrate a moral compass.

I have formal training in the first three disciplines. Multiple engineering degrees, an MD with a pediatric residency, and a lifetime of course work in ethics and Lutheran theology. Compassion, the lifeblood of pastoral care, is different. It is effervescent, overthrowing the Vulcan discipline of the other fields, rendering them messier but more human. Pope Francis embraces pastoral compassion and mercy. He is inspiring. He would have treated Charlie. He might be right. But until the Church better understands the discipline of science and technology, I can't rely on the accuracy of his opinion. I suppose that is very Lutheran of me.



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Grieving Youth in our Faith Communities

BJ Larson and Allison

AS IS THE CASE with adults, the death of a loved one is one of the most stressful events that a young person will endure. As children grieve, the faith community can serve as an important resource for the whole family. Based on firsthand accounts and the shared witness of many other youth and families who have journeyed through grief, we intend in this article to highlight the incredible healing capacity of faith communities who understand how youth and teenagers mourn differently than adults. Whether the death is due to cancer or completion of suicide, adults can be uncomfortable or lack knowledge about how grief affects kids.

A good place to begin in the faith community is incorporating education about how youth grief is impacted by the developmental process as a part of lifelong learning. A child who is old enough to love is old enough to grieve; however this grief is affected by developmental age of the young person, along with the nature of their relationship with the loved one who died. Additionally, young children's grief can be hard to spot because they grieve in small doses; one minute they can be crying, and the next minute they go out and play. Children learn and work by playing; it's how they process information. For young kids, using the words "dead or died" and breaking down the other words and what they mean is helping in beginning to understand.

A child who is old enough to love is old enough to grieve.

Since the funeral planning is part of the first days after a loved one has died, faith communities can model how to attend to the unique aspects of youth grief. Begin by acknowledging children as part of the family affected by the loss. This is true when a grandparent dies, as well as when a parent, sibling, cousin or friend dies. Help to prepare kids as to what to expect if this is their first experience with a funeral. Explaining commonly used terms related to death and funerals will help them better understand what is going to happen. You may ask directly how they'd like to remember their loved one.

In particular, one suggestion is to offer youth choices about how they want to participate in the visitation, including viewing the body or cremains or not, as well within the funeral/memorial service itself. Since we often orient funeral services more to an adult understanding, consider reflecting on how the readings, music, message and prayers speak to youth as well. And because the demands of this time can also feel overwhelming, the presence of other caring adults can be very helpful when a child needs a break to process apart from a public setting. For example, another member of the family/faith community such as a Sunday school teacher or youth leader can be ready to offer respite, or childcare can be offered, if a young

person needs to leave the funeral service for a time. This may also serve the adults in the family who are actively grieving and worried about their kids at the same time.

Grief shows up in many ways: physical, emotional, mental and spiritual. Grief affects our sense of security, including finances, which may mean changes in school, work or living arrangements too. Because youth often do not possess the language skills, intellectual maturity, or previous experience to discuss death and the emotions they're feeling in concrete terms, it is not uncommon for young children and adolescents to present with physical and emotional "symptoms" of grief. Stomach aches, headaches, insomnia, sleeping excessively, a loss of or increase in appetite, memory problems, constipation or diarrhea, frequent colds or sore throats, irritability, anxiety, and difficulty concentrating are all symptoms that have been linked to grief in children. The absence of symptoms or a marked improvement in behavior may indicate that the child is doing their best to act as if nothing has changed or upset their world as a coping strategy. On the other hand, behavioral problems such as fighting, hitting, or biting can also emerge.

Still young people who experience a death in their family can learn to live with this significant loss and the role of supportive adults and peers is a key resource in the healing process. Being supported by others who can validate their experience is important. Letting them know that what they are experiencing is a normal response in grief can be healing. Sometime adults ask the parent(s) how their kids are doing. Remember that asking directly or providing openings for youth or teenagers to share how it is for them, can be very healing. Know that play, drama, art, story, and music are also great gifts available to help youth give expression to underlying thoughts and feelings. Young people often do well with activity-based grief support rather than just talking about it.

A lot of times kids want to protect their parent(s), so they won't be open with their feelings for fear of making their parents cry.

Along the grief journey, spending time with other kids who have lost a parent or sibling can provide a sense of normalcy. A support group provides a place to grieve with others who get it. A lot of times kids want to protect their parent(s), so they won't be open with their feelings for fear of making their parents cry. This can delay the grieving process or make healing more complicated. Attending a support group series together has helped many families share more together about their grief. Grief is a normal part of being human, and grief is sometimes complicated in degree or intensity. If young people have consistent decline in school performance, persistent sleep problems, and are chronically unhappy or if they exhibit signs of long-term denial or talk about suicide, knowing when to seek additional therapeutic help is also important.

Since youth grief can be revisited during developmental milestones such as entering kindergarten, moving from elementary school to junior high, learning to

drive, or graduating from high school and heading to college, a faith community that is aware can honor important dates and events. For example, “A Blue Christmas” service for grieving families or other significant offerings can make a difference for young people who are living with grief. Using times of remembrance and ritual to help support the grief journey by marking significant transitions, anniversaries, and times of remembering, can help youth and families incorporate their loss over time through the various stages of life.

For example, Allison and I met this summer at the senior high beach camp our church offers every couple years for youth to reflect on their experiences of the intersections of faith and life. Walking back from the beach, I was wearing a back pack from Camp Erin Twin Cities, a grief camp sponsored by Fairview Youth Grief Services (YGS) since 2009, which serves kids ages 6-18 who have experienced a death loss.

Allison saw the backpack and we began talking. Here’s some things Allison would like you to know about

her story: Her dad completed suicide when Allison was 15 years old and her younger siblings were ages 13 and 10. For Allison and her family, the church has been a source of tremendous support: “When I look back on the last three and a half-years, I see my congregation and pastors being there for me right away with prayer and support, meals, rides, money to help pay for gas and groceries, and most importantly, quality time. I found it absolutely amazing though, that they were not afraid to come speak to me and ask how I was doing and have a conversation. Church members and workers never dodged us, while some others in the community did. It was a little hurtful to see that.”

She added: “All I know is I wouldn’t have made it this far without my faith in God. And what is so wonderful about a church congregation is many people struggle at some point, whether it be cancer, divorce, death, surgery, and so on. Congregation members are able to support one another by giving each other hope that God is with each of us.” Allison was confirmed in 8th grade at her LCMS congregation. Her confirmation verse from Jeremiah 29:11 has been very meaningful to her: “For I know the plans I have for you,” declares the Lord, “Plans to prosper you and not to harm you, plans to give you hope and a future.”

Like many other youth, grieving has still been difficult for Allison and she has felt dodged by others who have been afraid of talking with her. Transitioning to college has been both exciting and challenging and friends in Christ have been her rock. She has found that God sometimes is hard to recognize in the midst of the challenges. And it has been her brothers and sisters in Christ who have been beacons of God’s presence through it all.

“When I look back on the last three and a half-years, I see my congregation and pastors being there for me right away with prayer and support, meals, rides, money to help pay for gas and groceries, and most importantly, quality time.” –Allison



As a pastor and hospital chaplain, I have learned a lot from my experiences with loss and from getting to know youth like Allison. As a parent I know that I can want to protect kids from hurt or provide reassurance too soon, but I am called first of all to listen to the concerns they bring and the deep grief they carry. For me, the verse from Isaiah “and a little child shall lead them” holds a lot of truth. I am in awe of youth like Allison, who with a little support and care, find a way through the loss of a loved one. These young people model sensitivity, deep compassion and don’t take life for granted. We can learn a lot from them, as together we are the church, connected in what Martin Luther described: the “mutual conversation and consolations of the saints.”



BJ Larson is a system director for Spiritual Health Services, Fairview Health Services. Her background includes a BA in psychology and religion from Luther College in Decorah, IA; a master of divinity degree from Luther Seminary in St. Paul, MN, and a master of arts in organizational leadership from St. Catherine University in St. Paul, MN. BJ lives in Apple Valley, MN, is married and has two daughters.

A Bridge to Emotional Wellness

Kristin McKenzie

AS A PSYCHIATRIC MENTAL HEALTH NURSE PRACTITIONER, my day's work consists of evaluating and treating children, adolescents, and families who are struggling with a variety of emotional and behavioral problems. Many of those clients have a comorbid diagnosis of either a learning disorder, mood disorder, or very often a trauma-related disorder. Giving children and teens a safe space to talk about feelings and their experiences is central to my line of work, along with performing a thorough assessment. Ministers are vital players in the community that can reach out to the younger population and provide a listening ear, as well as promote health & wellness. As a Doctor of Nursing, my approach to clients is holistic in that we focus on the whole person, including the interconnectedness of their mind, body, spirit, emotion, and environment.

I believe the nursing model supports my core Lutheran beliefs, which both directly and indirectly influences my daily work. My Christian faith is conveyed in the way I engage my clients, but this is not something all people will find when receiving mental health treatment in the community. I find that encouraging clients to tell me about their relationship with God helps to avoid discussing the specifics of religious practice, helps them focus inward and to reflect on their emotional connection to God. This is the more important aspect of faith which allows me to explore their core beliefs and needs.

The care I provide to patients as a Doctor of Nursing is enriched by my Lutheran faith. I do not hesitate to recommend prayer, religious services, worship, music and spiritual-based counseling to my clients. I also have observed a significant need for my patients to connect with other persons of faith in the community who can help restore their spiritual wellness. I feel that God has answered a prayer of mine by providing this opportunity to speak to Lutheran pastors, chaplains and pastoral counselors as a mental health professional. I hope to provide some insight into the world of psychiatry, and how this relates to you and your ministry among those you serve. I believe that ministers and mental health providers are in a unique position to work together to improve the emotional wellness of our communities.

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Partnership

While planning what to write for this article, it occurred to me that both in ministry and in psychiatry people from the community come to us for help in solving some of their most personal and difficult problems. Not only do we have the same risk for a mental health disorder that any other population of people have, the stress of our jobs

can be a heavy weight to carry without the right amount of counseling and self-care. Everyone deserves emotional wellness. Meeting with a mental health provider for counseling can improve your emotional state while also providing an opportunity to learn more about mental health treatment. If and when the signs of a mental health disorder emerge even nurse practitioners and ministers can benefit from psychiatry.

Knowing what to look for and how to help is important for ourselves, our families, and for the people we serve. Recognizing our specific role and when to refer and collaborate with other professionals is essential.

As a psychiatric provider, my role is to diagnose and educate people about the neurobiology and treatment options for a variety of mental health disorders; and then, I prescribe medication if appropriate or necessary. The mental health clinicians I work with are specialized in providing trauma-based counseling, cognitive and dialectical behavioral therapies, interpersonal as well as family counseling, along with other forms of therapy specific to certain populations.

Recognizing our specific role and when to refer and collaborate with other professionals is essential.

I highly recommend referring persons that you counsel in your day to day ministry to a local trauma-informed mental health clinic if they have experienced any form of childhood trauma or adverse childhood so that specific diagnostic evaluation and treatments can be provided. This will improve your ability to minister to the spiritual needs of those you serve in the parish and in local medical centers. A trained trauma-specialist can provide types of psychotherapy such Eye Movement Desensitization and Reprocessing Therapy (EMDR) and Progress counting. With the coaching of a therapist, clients practice techniques that will help them manage the emotions connected to trauma and prevent flooding and flashbacks from occurring while processing the memory. When you encounter trauma victims during your ministry work, referring them to a trauma-informed mental health clinic can complement and improve your pastoral services. Most people in trauma counseling, or psychiatry, would benefit greatly from having another form of community-based counseling in a hospital, school or church setting. This can allow them an avenue to work on their present emotional wellness instead of focusing on the past or the physical treatments.

There is a particular need for a trauma-informed approach when dealing with children and adolescents that display behavioral health problems. During the pre-teen to early young adult age, the brain is experiencing rapid development. The positive reward circuitry of the brain, and the limbic system, are more active, meaning young people are more excited, more motivated, and they feel things, like emotions and physical stimulus, more intensely than people of other ages. When this is then coupled with reduced impulse control, or negatively impacted by a traumatic experience, the chance for high-risk and dangerous decision making goes up. Recent

trends show that the increased time spent on tablets, smartphones, and social media have actually reduced the amount of high-risk behavior that teens are experiencing. Yet at the same time, there has been a dramatic increase in mental health disorders for this population, including an increase in suicidal acts and self-injurious behavior. Specifically asking children and adolescents about bullying or about negative experiences with peers, parents, or the public will encourage them to open up. When questions are not specific enough, a child may not readily disclose something that is bothering them, because they think the adult will not understand what they're talking about or how they are feeling.

Effects of Childhood Abuse

From a societal standpoint, the statistics about childhood abuse are alarming. Abuse occurs pretty equally across populations no matter what the race, culture, creed or background. That means we as Lutherans also want to be conscious of this problem when working in our communities. To learn more about how early childhood experiences will affect our health as an adult, please see the CDC's Adverse Childhood Experiences Study (ACE Study). This research project developed a rating scale, with 10 questions about ACE and then also a resiliency rating scale. The results of the study clearly showed a link between childhood traumatic experiences and increased incidence of serious chronic disease and social problems along with increased risk of committing violent or suicidal acts. At the same time that the ACE Study was being done, parallel research studying the developing brains of children located physical evidence that traumatic stress physically damages a child's developing brain. Go to www.Acestoohigh.com a news site specific to ACES, to find the rating scale and see how it is being applied. In the CDC study, religion was one of the factors considered, and those who went to church were not more likely to be resilient to trauma. However, children that identified having a teacher, minister, or youth pastor available to help and support them were much more likely to be resilient.

The reluctance to seek emotional help is high in young people, yet 75% of mental health disorders start prior to the age of 25 years old.

In 2016 NAMI¹ statistics revealed that 1 in 5 youth ages 13–18 years old were diagnosed with, or treated for, a mental health disorder (NAMI, 2016). Keep in mind that this number does not identify teens with undiagnosed mental health disorder symptoms, of which there may be considerably more. The reluctance to seek emotional help is high in young people, yet 75% of mental health disorders start prior to the age of 25 years old (NIMH, 2015). That means we need to start talking to kids about their emotional health before their symptoms are starting to disrupt their functioning.

When we meet with parents it's common to hear about some problems they may be having with their child or teen. Recognizing the opportunity to provide stigma

1 National Alliance on Mental Illness

reducing education or treatment referral is important! I imagine that Lutheran pastors, chaplains and pastoral counselors have all spoken to a worried family member who is wondering what they can do to help a loved one recover mental illness. I can't tell you how to field those kinds of questions but my hope is that you can feel prepared to sit down and have a realistic conversation with people about seeking mental health treatment. Let's put past difference between psychiatry and religion behind us as we recognize that there have made leaps and bounds in the field of medicine since the days of Sigmund Freud.

When talking about mental health disorders, it is first necessary to clarify that these are physiologic medical problems, not a matter of mental weakness. There is a real biologic difference between how and where in the brain we experience the emotion of sadness, compared to the areas of the brain impacted by major depressive disorder. Here is a quick rundown: Changes found in the brain (such as the left prefrontal cortex in major depression) can be identified by 3 forms of imaging: MRI, PET scan, and SPECT scans. Psychiatrists are implementing new treatments such as Trans-Magnetic Brain Stimulation that has proven to be more effective than medication in many treatment resistant patients. The FDA has also approved a new brain scan that can confirm a diagnosis of ADHD. Genes for schizophrenia and bipolar disorder have been identified. Tests are being developed that can provide a more accurate diagnosis.

Pastors and chaplains are in an excellent role to walk with a person who is being treated for a mental health disorder and provide spiritually-based counseling or friendly advice during their path to recovery.

While testing becomes more specific, and the treatment options become safer and more effective, all people with mental health disorders will still benefit from having a spiritual connection to God. I believe they may not find full recovery of their symptoms without having faith. Pastors and chaplains are in an excellent role to walk with a person who is being treated for a mental health disorder and provide spiritually-based counseling or friendly advice during their path to recovery.

Normalize Mental Health Interventions

Now that we have discussed the importance of identifying mental health and trauma-related problems, I hope that you will join me in getting the message out to your community and to the Church. Do you think it is possible in your role to normalize the topic of mental health and intentionally reduce the stigma surrounding it? Since I am speaking directly to Lutherans, I would recommend arming yourself with the tools you need to clarify some of the moral conflict that Christian youth may feel in regards to mental health treatment. Encouraging more understanding of adolescent mental health with anti-stigma educational programs will help reduce the barriers to treatment.

Parents and children alike, may have a pre-formed belief that Godly people do not support mental health treatment, which may make them less likely to step forward when there is a problem. Being able to reduce their fear about mental health treatment can make the difference between showing up for their first appointment, or not. Here is my understanding of a few key issues that seem to affect my Christian client's and friend's opinions about mental health. I have never identified Bible passages that disallow God's followers to utilize science and medicine. On the contrary, Jesus himself promoted the idea of healing and found joy in reducing human suffering. I imagine you share my belief that our Father wants us to be well, both emotionally and spiritually, because in this way we will be able to do more of the work he sent us here to do.

Promoting emotional wellness is promoting good health. We can live longer to do God's work on earth. As Lutherans, we understand that our physical bodies are a temple of God. The Father charges us to take care of ourselves while on this earth, so that we may share the Holy Spirit with others. We can maintain our belief that Christ lives within us, and also accept that his presence does not prevent mental illness, just as it does not prevent cardiac disease. So many people feel ashamed by their mental health disorder and changing this stigma needs effort from everyone within our communities.

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Mental health disorders are complex in the way that they affect every part of our being, including spirituality. Depression, for example, impacts us physically, emotionally, spiritually and socially. Pastoral counseling, biblical study and collective worship within a community of Christians can greatly improve a person's emotional wellbeing. As a Lutheran, I know that psychopharmacology is not the only ingredient needed to restore livelihood and functioning for a person with a mental disorder. Jesus is the answer that will make a person whole. Proverbs 17:22 says it best, "A joyful heart is good medicine, but a broken spirit dries up bones."

Working with people diagnosed with mental illness can be tricky. It is important to consider how their functioning is impacted by their mental health problem. People are often guarded about sharing personal information, particularly if they have lived through trauma. Having a place where someone can be heard and feel safe to talk about their mental health, is a way for people to feel accepted. It may be easier for them if the minister can be the first to broach the topic of mental health, which can normalize the situation for them. This is where the bridge to emotional wellness can start to make a difference in people's lives. Don't hesitate to make a referral while also offering your own form of support.

A great way to help people struggling with mental health is to encourage them to learn more about their condition and symptoms. There are online resources that

provide valid information about mental health. Some that I would suggest are the National Institute of Mental Health and the National Alliance of Mental Illness websites (see below). You can request free brochures from them as well. In addition to these national websites, it is always a good idea to know the number for your local crisis hotline, so that you can link anyone with urgent mental health symptoms to a trained professional immediately.

There are key things that pastors can do for their parishioners to promote safe and effective utilization of mental health services. 1) To better understand how clients make decisions about their mental health treatment, *inquire* about their personal health beliefs, and any previous experiences in treatment. 2) *Assess* their readiness to change and likewise discuss motivating factors and barriers to treatment. 3) *Determine* any functional impairments such as ambulatory or transportation needs. The hassle of scheduling appointments, arranging transportation, and paying copays are just a few of the reasons that people are more likely to reach out to someone in the community such as a pastor, prior to enrolling in a mental health clinic. Clients may choose not to meet with their minister regularly while they are enrolled in a different form of therapy. However, when their formal mental health treatment ends, it can be very reassuring to know they have a supportive person in the community.

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In closing, my hope for this article is that its message can help create a bridge to emotional wellness between ministers and mental health professionals. Having pastors and faith leaders give direct referrals/recommendations for community based mental health assessment and treatment is important for our ever-changing society. Also, in the world of psychiatry we need to recognize and communicate the importance of spiritual health as part of recovery from mental health symptoms. A family system cannot work successfully if one of the members is suffering. For those ministers who work with an adult population, do not forget the importance of inquiring about other members of the family. This often can provide an opportunity to help a child whose Christian parents are nervous about seeking mental health treatment. I believe that if we work together, people within the church community can form a Bridge to Emotional Wellness that addresses mental and spiritual health needs for the children and adolescents they may serve.

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Kristin McKenzie DNP, PMHNP-BC, RN was baptized as a Lutheran and continues to be a practicing Lutheran today. She is a proud Godmother of two nieces; she lives in the town of Evans, NY with her husband, Kevin. She has worked in the nursing profession for the past 16 years and has been practicing Psychiatry as a Doctor of Nursing Practice since 2013. Kristin's doctoral nursing research, that demonstrated positive preliminary outcomes from using motivational interviewing to improve medication adherence in persons with Bipolar Disorder, has been published and presented in national medical forums.

She currently works as a Psychiatric Mental Health Nurse Practitioner at Child & Family Services of Buffalo NY, servicing individuals and families across the lifespan, starting at 3 years old. Kristin worked as a psychiatric collaborator for Samaritan Counseling Center, an organization that provides pastoral counseling services in WNY. She has been involved in Lutheran youth ministry in a variety of ways, including being a Sunday school teacher for youth ranging from preschool to high school. Her experience in working with children of faith drives her desire for the recognition and treatment of pediatric mental health disorders.

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Book Review: *Children Die, Too* *Children Grieve, Too*

by Joy and Dr. S. M. Johnson

A review of two resources from Centering Corporation and *Grief Digest Magazine*

I DON'T KNOW MANY chaplains who are not alert to the discovery of suitable and practical resources. If this is generally true, I suspect it is perhaps even more the case when children are a factor in our work. In my almost thirty years of professional ministry, I have frequently wished for just the right thing when I am called upon to respond to the myriad complications of those who are grieving the death of a child and of children who are grieving a death. *Children Die, Too* and *Children Grieve, Too*, by Joy and Dr. Marvin Johnson, co-founders of Centering Corporation, have been added to my “go to” list of resource materials.

More booklet than book, each is clearly designed to be purchased in quantity and shared with clients. *Children Die, Too* even begins with a page on which to record the name of the child who has died, along with the date of birth and death. Both booklets are written with short, titled sections that allow the reader to skip around for the part that is helpful at different times in their grief.

Children Die, Too tackles the heartbreaking reality that, though perhaps less frequently than in the past, children still do die. When they do, the grief is profound. Being able to help those who come to us with this grief is both a daunting and a sacred task. There is a lot of helpful information in these few pages to help assist us as we offer support and solace. The book begins with short sections on feelings and reactions parents might experience. It moves forward to how reactions may differ between spouses and then includes others who share the grief including grandparents, siblings and friends. Incorporated into the pages are words from parents whose children have died giving a sense of solidarity with those who have traveled this path. There does seem to be a presupposition, particularly when outlining common grief reactions, that the primary grievers are partnered parents with some connection to a faith framework. Though not a big problem against the other useful information, it did stand out to me when I first read through the pages. There is a short section directed to single parents and step parents. As a single parent myself, I thought it felt like an add-on and I wondered if a single parent facing the death of their child might feel further stigmatized by this distinction? Overall, however, what this book offers is not diminished by this critiques.

Children Grieve, Too offers clear and concise information for those journeying with children through grief. It has a good section, similar to what was in *Children*

Die, Too, with typical grief reactions for various stages of development adding “what you can do” suggestions for ages from newborn through teenager. With uncomplicated language, the book offers guidance for explaining death, funerals and visitations. It addresses not only what a parent can do for a grieving child, but also what a child might do in the midst of their grief. Here again the authors’ use of real language rather than images such as describing death as “like going to sleep” gives parents and other care givers practical suggestions for the very difficult conversations of grief work with children.

Although either or both of these titles could simply be given to families at the time of a death, I could also imagine them being used as part of a grief support group with each section receiving the group’s insights and experiences to add depth to the information presented by the Johnson’s.

But there is more! In addition to the fine content of both of these books, I am especially grateful for the comprehensive bibliographies, and the connection to the Centering Corporation website: <https://centering.org> If you are not familiar with the fine resources available through the Centering Corporation, I highly recommend perusing the site.

The waters of grief always require skillful navigation. I am confident these booklets will help many as they journey toward healing.



Reviewed by the Rev. Ghislaine Cotnoir, Director of Pastoral Care, The Artman Home & The Hearth at Drexel in Ambler, Pennsylvania. She serves on the Caring Connections editorial board.

News, Announcements, Events

Upcoming 2019 Zion Conference

The next triennial Zion Conference will be held at St Mary's Seminary and Retreat Center in Mundelein, Illinois. Proposed dates are October 10–13 or 17–20 of 2019. Zion Conference has been a tradition for many years as Lutheran chaplains, pastoral counselors and clinical educators join for prayer, camaraderie, education and renewal. The ELCA and LCMS have continued to be supportive of this joint event. The last event in 2016 was held near St Louis and was planned by the LCMS. This year, the conference is being planned by the ELCA with the leadership of David Kylo. Watch for more details to come.