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The Best Caregivers Care for Themselves

### END-OF-LIFE CARE

"The best caregivers care for themselves." You are listening to ReachMD XM 157, the channel for medical professionals. Welcome to the clinicians' roundtable, I am Susan Dolan, your host and with me is chaplain, Mary E. Johnson, assistant professor of Oncology at the Mayo Clinic College Of Medicine, in Rochester, Minnesota. Chaplain Johnson has provided spiritual support to patients, their loved ones, and staff at the Mayo Clinic for nearly 30 years. Chaplain Johnson, welcome to the clinicians' roundtable!

#### CHAPLAIN JOHNSON:

Thank you Susan, it is great to be here!

#### SUSAN DOLAN:

What do you like most about your job?

#### CHAPLAIN JOHNSON:

Well, I come to work every day, and I do not think about it as a job, it is a privilege. I get to sit at peoples' feet and listen to their stories, and if I am fortunate and the winds are blowing at the right direction, a relationship begins, and often the relationship begins in the midst of a very trying time for them is there in the midst of a health crisis. So, what I appreciate most about my job is the sheer privilege of it.

#### SUSAN DOLAN:

What is the most challenging part of your job?

#### CHAPLAIN JOHNSON:

Well, I think that working in a high acuity environment like a hospital, the most challenging part of the job here is not to take it for granted and to never forget what it is we are called to do here. When I do staff development presentations, I ask people what they hear when

they are at a social gathering and they tell people what they do for a living and these people might be nurses in a neonatal Intensive Care Unit, they might be hospice workers, they might be anesthesiologist, and I asked them questions because we come here every day and we work with people who are in many times desperate situations, and I think it is easy for us to actually forget what it is that we do because we get so used to it. So, the most challenging part of our job, and I will speak for myself here, most challenging part of hospital ministry for me is to remember that these are extraordinary times in peoples' lives, and even though I have been in these clinical situations many, many times. This is the first time for a lot of people and it is really good to just remember this is wonderful opportunity that we have here to journey with people through some of the most amazing times in their lives.

**SUSAN DOLAN:**

Tell us about the most common reasons doctors turn to you for support and what do you tell them?

**CHAPLAIN JOHNSON:**

Clearly, the most common reason the physicians turn to me and turn to my chaplaincy colleagues for support is when they have not met their own expectations. Either they have not met the expectations for the culture of medicine, which is to cure and to make better and to eliminate suffering, simply because of the circumstance of the situation or they have not met their personal expectations about being able to most of the times eliminate suffering. I think the way that these values are inculcated in the culture of medicine or really often times setting physicians up to be more than any human person can be, and so we spend a fair amount of time here listening to people sort these things out for themselves and offering them reassurance and counsel about the role that humanity can actually really play in their ability to be in good useful relationships with their patients.

**SUSAN DOLAN:**

Would you advise healthcare professionals about self-care when working with terminally ill patients?

**CHAPLAIN JOHNSON:**

That is a really good question because I think sometimes chaplains are the worst at self-care and reason for that is because our work is so difficult to evaluate, and so we have this sort of sometimes capricious, not very clear way of saying, "yes our work is finished," or is not, or job well done or job not well done. So, we are probably in one of the worst positions, but we have a role in the support of our colleagues in the multidisciplinary team, and here at Mayo, part of our mission statement in the department of chaplain services is to care for the soul of the institution, that is what that means is if we really need to be cognoscente of the needs of our colleagues on the multidisciplinary team and so we advise as issues and challenges present themselves. I think one of the main things that we encourage people to do is to take care of one another and one example of that would be to notice and to complement the job well done. Another example would be to notice and to acknowledge the difficult task once it is finished. When things get so busy, these simple gestures fall by the wayside, but they can really do a lot as an investment in a multidisciplinary team and the cohesion of the team when you know that your colleagues are really pulling for you. So, really, a lot of what chaplains do is to help to build up the team.

**SUSAN DOLAN:**

If you are just joining us, you are listening to the clinicians' roundtable on ReachMD XM 157, a channel for medical professionals. I am Susan Dolan, your host, and with me is chaplain Mary E. Johnson, assistant professor of Oncology at the Mayo Clinic College Of Medicine in Rochester Minnesota.

**SUSAN DOLAN:**

Chaplain Johnson how do you cope with taking care of so many dying patients and their loved ones?

**CHAPLAIN JOHNSON:**

I think we need to acknowledge that being in a medical environment different disciplines in the medical environment have different goals, and as you can imagine for people in ministry death is often not the enemy and suffering is not the end of the story. So, persons coming to the end of life, for chaplains, this is not a failure or this is not perceived to be a failure like it might be for some other disciplines in healthcare. Our job is to be with people wherever they are and the job well done is faithfulness at that task. So, coping with persons, who are dying is the same as coping with anyone else along the trajectory of healthcare. We need to be faithful to them. When it comes difficult to be faithful to them, it is very, very important for me and for my colleagues to get some help to get some consult to be able to have at least one other person in our life with whom we can be completely honest and we can discuss our concerns, and you know sometimes things come up. The person in my care might remind me of someone in my personal life for whom I have very strong feelings or perhaps the person in my care may have had a long, long journey of suffering, and I think again, people in healthcare sometimes forget the cost of witnessing other peoples' suffering on us, the cost to us, so it is important for me and for my colleagues to keep these things before us, and it is really a day-to-day thing. No 2 days are the same and it is very important to be honest with ourselves about our own needs.

**SUSAN DOLAN:**

How do you help patients and loved ones forgive one another?

**CHAPLAIN JOHNSON:**

That is another great question. Forgiveness is a very common task for people as the end of life is approaching. Ira Byock wrote a wonderful book about the final messages that people need to exchange near the end of life and two of those messages almost half of the messages that he is talking about have to do with forgiveness. "I forgive you, please forgive me." This is a way of bringing closure to a relationship and acknowledging the totality of a relationship that may have involved hopes and dreams, may have involved failures, betrayals, hurts, joys, the whole gamut, and if we are going consider a relationship as closing because of the end of mortal life, it only follows that people will need to forgive or could need to forgive and be forgiven. So, the first part of this task as opportunities present themselves is to normalize this process and to suggest to people, who by listening may be discerning they are struggling with either the need to forgive someone else or to be forgiven is to facilitate that process and to help them move forward through that process. In my own approach to this particular opportunity in patient care, I tend to think that people know in their own hearts when this is the need, but they do not always know how to do it, so how do we help patients, is to listen to the true nature of their need first and then to facilitate a process of forgiveness. Now, depending upon their religious background or their spiritual beliefs, they may need to ritualize this in one way or another and some religious bodies, church organizations have ways of ritualizing forgiveness through sacraments or rituals that actually give persons an opportunity to include the divine, the power greater than themselves, in this process.

**SUSAN DOLAN:**

What advice do you have for people who are grieving?

**CHAPLAIN JOHNSON**

You know what I find myself telling people who are grieving more often than not is please give yourself a chance to do what you need to do to grieve. In this culture in the West, we have almost institutionalized grief and if you look across the board, company policies about funeral leave, you will notice that we are giving people days to weeks to do the initial grief that they need to do after the loss of a loved one for instance, then we want them back on the job. We want them functioning fully and there is such a fallacy. We know that a lot of grief processes take at least as long as the relationship itself and I think the conventional wisdom about grief is after a couple of years have passed if you are not doing as well as you think you should be doing then you should seek some professional mental health support because there are people for whom grief is complicated and takes longer for one reason or another and it is perfectly understandable that perhaps a professional could help facilitate that process for them, but I think bottom-line on advice for people for grieving is give yourself a chance to grieve, give yourself the time and put yourself in the relationship that support that process. We all have people in our lives who can stand to see us when we are sad and weeping and people in our lives, who cannot and they will try to talk us out humorous out of it. I think it is important for us at least for a period of time as human persons all they have a chance to grieve and to grieve well and sometimes grieving well involves time and it involves a supportive environment.

**SUSAN DOLAN:**

What do you tell people who are struggling with guilt?

**CHAPLAIN JOHNSON**

I have not met a person who is struggling with guilt as the end of life approaches or I should amend that I should say I have never met a person who is not experiencing some guilt, again, a very normal part of coming to the end of life and trying to bring closure to a relationship. It is part of being human to wonder if we have done well or to wonder if we have not failed someone. Again, this is the process that needs to be normalized. Guilt is a normal part of grief; it is a normal part of anticipatory grief, which is grief that happens actually before the loss occurs. When you learn that you are coming to the end of life, your loved ones do not start grieving at your funeral, they will start grieving the minute they get the bad news. So, it is important if people are seeking our assistance with guilt to try to understand what it is they are struggling with, and if your loved one or a friend who is with someone who is struggling with guilt, sometimes they need a professional person to help them with that or sometimes they are going to choose you because you are the safest person in their life. Guilt is something that renders us vulnerable and it is not easy to share that with another person. So, I think it is important for people who feel guilty to know that is pretty normal.

**SUSAN DOLAN:**

Chaplain Johnson, thank you so much for joining us to discuss end-of-life care.

**CHAPLAIN JOHNSON**

It has been a pleasure Susan and good luck in your work.

**SUSAN DOLAN:**

I am Susan Dolan and you have been listening to the clinicians round table on ReachMD XM 157, the channel for medical professionals.

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Thank you for listening.

Hello, this is Peter Farrell, Vice-President, of Abbott Point of Care, the vision of Abbott Laboratories and you have been listening to ReachMD XM 157, the channel for medical professionals.