



INTERVIEW TRANSCRIPT

DISCUSSIONS WITH WORLD-LEADING EXPERTS

Living With Migraine Through Times of Grief & Loss

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Introduction (00:04): Grief is one of the most profound and difficult experiences in life. And for someone living with migraine, the intense stress and emotional pain of losing a loved one can trigger a devastating cycle of physical illness, making it feel impossible to cope. How do you navigate bereavement when your own body is working against you?

Introduction (cont.) (00:26): Dr. Dawn Buse is a clinical professor of neurology and a leading health psychologist who has dedicated her career to helping people manage the immense burden of migraine. In this interview, she'll offer compassionate and practical guidance for anyone facing the dual challenge of grieving a major loss while living with migraine. Dr. Buse, welcome back to the Migraine World Summit.

Dr. Buse (00:50): Thank you, Elizabeth, and hello to everyone joining us.

Elizabeth DeStefano (00:54): So, Dr. Buse, to start, can you frame for us why the experience of grieving a major life loss uniquely complicates the challenges of that for a person who also lives with a chronic illness like migraine?

Dr. Buse (01:11): Grief is an overwhelming experience. It's an emotional experience, a physical experience, a life-changing experience in so many ways. Of course, living with migraine is no easy feat. Living with migraine is living with a chronic, primarily unpredictable, painful disease with attacks that strike without warning most of the time. So both migraine and grief really take things out of our control — which is scary, uncomfortable, frustrating, angering.

Dr. Buse (01:48): They're both overwhelming physical and emotional experiences. So layering the two on top of each other is just a lot for any human to handle. It's not that someone is not coping well or they're not strong. Grief and migraine are both huge experiences for the mind and the body.

Elizabeth DeStefano (02:10): How can physical components that often accompany grieving — whether that's crying, sleepless nights, stress that's constant or intermittent — provoke migraine?

Dr. Buse (02:26): What a good question. So you mentioned several things that would change our routines. And we know that for someone living with migraine — or for humans in general — routine and consistency in healthy lifestyle habits are really key for keeping the nervous system happier and a little more calm. And that includes routine and enough quality restful sleep, eating regularly, staying hydrated, getting a little movement or exercise, and some social activities or hobbies — all of those things.

Dr. Buse (03:03): All of these routines can be very disrupted by the experience of grief — especially very early on in the process where someone may not be sleeping well at all, may not be able to fall asleep, or maybe not able to stay asleep, or sleeping around the clock, like it's hard to get out of bed.

Dawn Buse (03:25): Someone may be in the shock or depression aspects of grief where they have no appetite, or perhaps they are comfort eating and eating more than they normally would — probably not taking care of themselves the way that is best for anyone. And we know that. And we want to give someone going through a grief process a break to know that this isn't a time when we expect that you can care for yourself.

Dr. Buse (03:56): Hopefully there are others around who may be helping provide the structure and the support — maybe the healthy meals or the comfort meals. Or maybe it's time to talk to a doctor, your primary care even, about those experiences if the grief process has been going on — especially longer than six months or 12 months and someone's gotten past that first year milestone. But we really expect that there are all these disruptions to the normal human cycle because loss — the death of a loved one — is disruptive to every aspect of life.



Elizabeth DeStefano (04:35): Those factors that are so important to supporting migraine — being attentive to things like our sleep and our eating and movement — can be hard enough to manage when we're not grieving. So certainly it becomes so much more challenging to maintain while we are.

Dr. Buse (04:57): Absolutely. When someone is in a grief process, especially early on, thinking about self-care is really tough. They're probably thinking about other things. They may be in the very deep emotional experience of sadness, depression, anger — all of those experiences and emotions that come from loss. And at the top of their mind is probably not taking care of themselves in that moment — even though it is a time when self-care is actually really important, but it's not easy to do at that moment.

Elizabeth DeStefano (05:37): Many people in our community describe grief-induced migraine attacks as some of the most severe and relentless they've ever had. What is actually happening in the brain and the body that forges such a powerful link between powerful emotions — like the emotional pain of loss or other strong emotions — and the physical pain of a migraine attack?

Dr. Buse (06:02): Well, the brain is part of the body, and we know that the thoughts we have in our mind are intimately connected to our physiologic experience throughout our whole body. The neurotransmitters and neurochemicals that talk to each other in our brain are part of the pain experience, as well as part of all the emotional experiences.

Dr. Buse (06:21): There are in fact several parts of the brain that are both involved with migraine attacks as well as pain — physical pain and emotional pain or depression — such as the amygdala or the anterior cingulate cortex. So what's happening is that those parts of the brain are especially activated. Physical pain can be experienced as emotional pain and vice versa. And really, there are neurotransmitters and chemicals in the brain communicating with each other that are active for both physical and emotional pain.

Elizabeth DeStefano (06:57): This really demonstrates that true mind-body connection and how relevant this is if someone is experiencing or facing loss. So it is not simply the stress. It is a neurobiological pathway that connects powerful emotions and physical manifestations that we're experiencing. I think that's important for people to know.

Dr. Buse (07:24): Absolutely. These are innate biologic survival mechanisms. These are evolutionary biologic mechanisms — both the response to physical pain, such as migraine, and the response to loss — because these are dangers. And the amazing human brain protects us from danger by signaling extreme distress when we're in danger. So we think about two kinds of dangers going on at the same time, one being the feeling of pain. The body and the brain interpret that as danger to oneself and react with these ways of alarm, telling us that we're in danger and there's physical pain going on.

Dr. Buse (08:05): And then grief or loss goes way back evolutionarily to when we're infants and we attach to our caregivers, a mother or another caregiver. That attachment is our survival as an infant. If we are lonely, if we are missing our caregiver — our mother or father or other primary caregiver — we feel distress. We feel scared and nervous. We cry. We get that attention: "Come back. I need you to take care of me." So when we experience loss — the death of a child, death of a parent, death of a spouse — we are losing someone very close to us. And our very deep, innate, instinctual brain is saying "danger and pain." We're missing a close connection. And those close connections are very important to our survival and well-being.

Elizabeth DeStefano (09:01): So our brain is really doing a great job to try to alert us to a problem and not necessarily differentiating between whether that's a physical danger or a very serious emotional one that is evolutionarily very important to us, right? And I think that points out how we should be aware of the vulnerability we may experience to migraine attacks — not just when we are physically at risk, but when we are emotionally at risk because of grief or loss.



Dr. Buse (09:35): A really well-done study called the Headache Prediction Study — the HeadPRE study — found that it was changes in multiple factors which put someone at vulnerability, raised vulnerability for an attack. And so increased stress is a predictor of attacks. Decreased stress is a predictor of attacks. So what is going on is changes in our protective system that responds to stress.

Dr. Buse (10:04): Our fight, flight, or freeze system — when it goes up, certain neurochemicals are released, certain things happen in the body to try to protect us. It stays at that level for some period of time. And what's happening during grief for some people is they may be staying at this heightened alert type of place with their sympathetic nervous system for long periods of time, which is physiologically exhausting. We're only built to be on alert for a very short period of time. And then all of that energy, adrenaline, cortisol — all the physiological responses — are intended to relax.

Dr. Buse (10:44): Well, when it stays heightened — that heightened awareness, that heightened on-guard situation for our nervous system — it's hard on our body. And then you would think, "OK, now I've relaxed. I've calmed down. The threat has passed." Or even something more simple: "My finals week is over." "The birthday party for my child is done. It went well. I should be able to relax, right?" Well, no. That is actually a second time when someone is at increased vulnerability for a migraine attack.

Dr. Buse (11:16): As those stress hormones drop down rapidly — another change. The migraine brain likes consistency, not change. And that puts someone also at risk for a migraine attack, possibly because those corticosteroids that are released with stress actually are protective from physical and emotional pain to get us through the emergency: We need to get out of the burning building. We need to take care of whatever we're doing. We need to finish our finals. We need to take care of our child in this moment.

Dr. Buse (11:48): And then it's not until the threat or the stressful situation has passed that we see this calming of the nervous system. So with the changes that happen — increases and decreases — we can have increases in risk of attacks. The same study found the same thing was true for more sleep or less sleep. So all of these changes, even when you think, "Oh, this is good. I'm getting more sleep. I'm going to feel better. I'm going to rest up."

Dr. Buse (12:19): Actually, that can again throw off the nervous system, who's really happiest with routine, consistency, and balance. So the experience of grief is a roller-coaster of physiologic reactions, emotional experiences, and physical experiences. And it's keeping someone in this change state, which is increasing the risk of attacks.

Elizabeth DeStefano (12:47): Is there anything we should understand about the relationship to the person that we have lost and the impact of that connection on our grief and impact on migraine?

Dr. Buse (13:04): A wonderful grief researcher said that grief and love are two sides of one coin. And the stronger you love, the stronger you grieve. So when we think about losing close connections, close loved ones — they may be a child or a parent, a spouse, or someone who's very close to your heart even if they don't have a traditional defined role.

Dr. Buse (13:33): It is the human experience. Beyond humans, elephants grieve. It is the experience of beings to honor that love and loss with this emotional grief — emotional and physical grief response. This is the expression of love and loss. And it's what we expect. This is the process of living life that happens to almost everyone, usually more than once at multiple points during their life.

Elizabeth DeStefano (14:08): And there are some relationships that may not rise to the top of some people's minds when they think about loss, but as you said, could be less defined roles — roles that don't have a label but still have closeness. Could this also apply to very special relationships with perhaps pets, for instance?



Dr. Buse (14:27): Absolutely. Pets, to some people, are very close parts of their family and have very strong, caring, loving relationships, as well as commitments. When you have a pet, you have a job. You are the caretaker. You've got to make sure they're fed and walked, if that's the case, or have everything that they need. And one aspect of grief is the loss of a role, which could be the loss of a caregiving role. Pets can bring so much joy into life for many, many people.

Dr. Buse (15:04): And some people, their pet might be the only being who they live with, and that pet they interact with constantly throughout the day. And they have a strong connection to that pet as part of their daily routine, part of their daily life. I had a cat when I was in graduate school, through internship and fellowship, that moved with me for my first job. We were incredibly close. I talked to Charlie, my cat, throughout the day, all day, every day. We really interacted.

Dr. Buse (15:38): And Elizabeth, I'm so glad you mentioned the major role that pets have in many people's lives and how significant their loss can be. In fact, when we were creating our new clinical trial endpoints from the FDA-sponsored MiCOAS [Migraine Clinical Outcome Assessment System] study, we interviewed people with migraine multiple times to help develop these questionnaires.

Dr. Buse (15:58): And one thing that came out of our qualitative interviews that several people reminded us of is that our preexisting instruments had always asked about missing work or school, and caring for children — but we didn't have pets in our questions. And in fact, for some people, caring for their pet can be a real challenge during migraine attacks.

Dr. Buse (16:20): For example, one woman who has a dog and lives in an apartment in the city reminded us that if she can't get out and walk her dog, no one can do it. And her dog needs to go out and go to the bathroom. Her dog needs to be fed. So pets play a significant role in our lives. The loss of pets can be a major grief experience for people. And the disability associated with migraine can sometimes interfere in the role of a caregiver for your pet.

Elizabeth DeStefano (16:51): I'm curious to explore how psychologists view approaches to coping. And a lot of our listeners may have heard of models like that from Elisabeth Kübler-Ross, or perhaps more recently something called the dual process model. Could you explain a little bit about those types of models and then how they might apply to coping while living with migraine?

Dr. Buse (17:19): Absolutely. I agree. I'm guessing a lot of people have heard of Elisabeth Kübler-Ross's stages of grief, which includes stages such as denial, bargaining, and then ultimately moving through to acceptance. And you've probably heard of that in books and on TV and in media. I know in [the U.S. TV show] *The Office*, Michael [Scott] talks about the stages of grief. And the idea being that people kind of move from one to the next, although she did mention that people could move back and forth.

Dr. Buse (17:51): Well, interestingly, Dr. Ross actually created that model for people who themselves were facing a terminal diagnosis, specifically people with later stage cancer. So it really applied to the individual themselves. But we've really applied it beyond that to anyone also coping with the death or loss of someone who's the survivor.

Dr. Buse (18:16): You also mentioned the dual process model of grief, which was first published in 1999 and talks about two different phases that people who are grieving may move through: The loss-oriented phase and a restoration phase. And in this model, people can move quite quickly within a day or hours or a moment from one to the other. And there's also a good amount of overlap.

Dr. Buse (18:43): The loss phase being that emotional and physical response to grief that we think of: the crying, isolating, thinking about memories, be they good memories or traumatic memories of a loss — guilt, rumination about things someone might have done differently to prevent an accident or a



loss, things they might have said to a loved one. That's all part of that real raw loss phase — emotional and physical.

Dr. Buse (19:15): Difficulty with the sleeping and/or getting out of bed, with not feeling social, maybe with not wanting to eat, not taking care of oneself — that loss phase, the emotions. And we don't need to push people out of that phase if that's where they are in the moment. If cocooning and just kind of nurturing oneself and even spending time in the memories feels like the right thing in the moment, that's where they should be.

Dr. Buse (19:48): Now, the restoration phase is turning towards what's next in life. Someone may have been a caregiver to an ill person for some time. That person has died, and now their time, their schedule is different. Their home may be full of equipment, medical equipment. They may have stopped working or be working from home, or have gone on medical leave to care for their loved one. All of a sudden, things have changed. So the restoration is a more busy focus: What do I need to get in order? Paperwork, finances, roles, housing.

Dr. Buse (20:32): And then there's also, when someone's ready, starting to explore what's next. Reengaging socially, reengaging with hobbies or finding new hobbies, figuring out what work looks like if someone's working or wants to return to work. All of those more forward-thinking and also kind of the checklist in life: What do I need to do?

Dr. Buse (20:56): And at times, that can feel overwhelming if it's very early on or someone really feels better to spend more time in that kind of cocooning, memory, let-the-emotions-come kind of phase. But then sometimes it can feel good to step into one of these responsibility phases because in some ways it kind of focuses their mind on a different task. "I've got to take care of this paperwork. I've got to do these legal things. Let's get the room changed up where that person had been sleeping or staying. Let's work on funeral requirements and arrangements, or a memorial."

Dr. Buse (21:45): Now this can happen forever. Grief can stay with us for the rest of our lives, especially in those major losses of someone who was a very close, important part of your life and that you had big love for. That grief experience may never go away. The journey may change and it may become more of the positive memories and less of the guilt or sadness — or it may not — but it may quiet over the years.

Dr. Buse (22:18): But in the early phases, the person is really pulled in these two directions: the emotions they're feeling, as well as the things they need to get done. And allowing themselves time in each space when they feel like it can actually be a positive, restorative way to cope.

Elizabeth DeStefano (22:38): So it sounds like looking at it this way could also be a way to sort of give ourselves or someone we're caring for permission, in a way, also to switch how they are approaching their grief in a given week, maybe in a given day, or even a given hour — not as avoidance, but as really a necessary strategy for coping with grief and maybe even managing their health.

Dr. Buse (23:11): Absolutely. Both roles are important. Allowing the time to grieve, feel the emotions, experience the memories — that is valuable and important. And if we are helping someone else cope with grief, we don't want to say that they need to move quickly to this more administrative phase, the restorative phase.

Dr. Buse (23:34): But it can also be a positive for that person to have a purpose, have some things they need to do, a reason to get up and get out of bed, a reason to get dressed and brush their teeth and make some phone calls or get outside. Those can be actually physically and emotionally positive experiences. But then the person, once they've done those tasks, may want to go back to that kind of cocooning, comfortable space and way of thinking for a while.



Dr. Buse (24:04): So allowing someone to judge when they need to move through these two phases and letting that happen naturally is what the dual process grief model is about.

Elizabeth DeStefano (24:16): OK, so let's make this very practical now. What are some specific areas that are important to think about when we are focusing on coping when our lives are turned upside down by grief or loss?

Dr. Buse (24:33): Absolutely. So whether we are thinking about this ourselves going through the grief or trying to help someone else, first allowing the time for grieving at one's own pace to feel the emotions and giving some real honoring to that time and experience. And again, that's the loss focus component.

Dr. Buse (24:55): Once we think about the restoration focus component, what are some things that will help the person start to feel some more — [*sighs*] I don't want to say normalcy — but just start to get a little bit of balance, a tiny bit of control back in life. One thing is routines. We know these routines are good for helping the person with grief continue on, as well as migraines.

Dr. Buse (25:23): So trying to get back to a good sleeping routine; trying to stay up during the day and sleeping at night — if that's your sleep schedule, some people have a different sleep schedule — but up for a period of time, sleeping when it's appropriate. If sleep is not going well, reach out for help from your primary care doctor. But also you can think about comfort things that help with sleep: a warm drink at night; making sure that your room is dark and quiet; considering relaxation exercises; soothing music; or whatever is especially comforting for that person. Have all those there.

Dr. Buse (26:02): Trying to think about a little bit of movement, getting outside, taking a walk — whatever that looks like for someone. Thinking about support — and hopefully there are people around offering support. Go ahead and accept it to the degree that feels comfortable for you. Do not feel shy to explicitly state how you'd like to be supported, whatever that is. You may like someone coming over and being with you — or you may prefer your privacy — and that's OK to say.

Dr. Buse (26:36): But instead of saying, "No, please don't come by," give that person something they can do: "You know, I haven't been grocery shopping. I'm out of milk. Can you bring milk?" Or perhaps you have a child or a pet: "Can you take my dog to the park? He really needs to get in a run." "Can you take my child for a play date? That would really make him or her happy. That would make me happy." So offer the people who want to help you a way to help that feels good to you.

Dr. Buse (27:07): And that can change — that can change day to day. Routines and all the healthy lifestyle habits; support, accepting the support that feels good; finding a place where you might want to talk about it to someone. It could be a counselor, a primary care professional; it could be someone who is in your faith. It could be a friend — just someone who's going to have a nonjudgmental ear and a kind shoulder to talk to may feel good.

Dr. Buse (27:40): It may feel good to join a support group, either in person or virtual — or even just start to listen in to what others are saying in various support group formats, even if you're not ready to share yet. So those are some of the things that on the restoration side can be helpful. Also, whatever is comforting or soothing to you: It could be journaling; it could be movement; it could be music; it could be a hobby. Who knows what that is to you? Try to start bringing some of that back into your life as you feel ready.

Elizabeth DeStefano (28:21): So really being able to think from the loss-oriented side of ensuring that we have the time and space to do and feel what we need to around our grief and loss. And then on the restoration side of things, being very attentive to trying to bring things in that have to do with routines — whether that has to do with movement, sleep, eating, and so forth; making sure that we use



the support or seek out the support that would help us in the ways that you offered. So those are great general strategies. How would they apply to something like planning to attend a funeral?

Dr. Buse (29:02): That's a good question. And a funeral or memorial will happen early in the grief process. The bereaved person is still probably very raw in her or his emotions. They're probably big emotions. And now she or he is going to go into a larger public gathering where there'll be lots of people wanting to give well wishes and well-intentioned advice that may or may not be helpful or might be annoying or offensive, even though it's well-intentioned.

Dr. Buse (29:35): So some things to think about are similar to planning ahead for a migraine attack. So planning ahead, rehearsing the day, thinking about what it's going to be like. What comfort items can the person bring with her or him? Similar to migraine: Is it going to be water or a drink, some hydration? Or perhaps a personal item of the deceased or a personal comfort item yourself? It could be a shell you picked up together on the beach that goes in your pocket, or a religious item, or a book, or a memento — something, some talisman to carry with you as a touchpoint when emotions get big.

Dr. Buse (30:26): Allowing yourself the permission to step out or step aside if needed. Maybe even figure out in advance where that might be. Is there a private room that you could step into? Or would you even want to walk out to your car and be parked around the corner? Prepare some places in advance.

Dr. Buse (30:49): Also, if you do have trusted friends, family, or even perhaps a funeral director, or a person of faith who's leading a memorial, or a ceremony, or a funeral — talking with them in advance about how you're doing emotionally, as well as the fact that you have migraine, and you could have a migraine attack, or some level of symptoms — letting them know what to expect. And having them help you make plans in advance.

Dr. Buse (31:22): So planning ahead, communicating openly — just like it's always good to do with migraine — and give yourself permission to step away, to leave early. Whatever it is that is comforting for you. Your grief, the way it is, is exactly the way it should be for you. There's nothing that you should do differently in this moment. There's no right way to get through this moment. So don't judge yourself harshly. Be gentle and kind to yourself.

Dr. Buse (31:59): And unfortunately, just like life with migraine, you will need to be prepared for advice that may be good and kind, and is almost always well-intentioned, but could be annoying or frustrating or angering. And it's a good idea to have a statement prepared. You may say something simply like, "Thank you for your thoughts, thank you for your caring," and step aside and move on to either the next person or just go into, again, that private space.

Elizabeth DeStefano (32:33): That's great advice. And I love the support you shared, too, that could be relevant for someone who might experience some guilt about prioritizing their own self-care for the purposes of their own grief — but also for the purposes of their health in stepping away — and that there's no one process that's necessary or appropriate, and that the individual has the right and purview to make those decisions.

Dr. Buse (33:00): Absolutely. We often feel guilty for prioritizing self-care, but self-care is not selfish. It is essential for you to continue functioning. And if you are caring for someone else — maybe a senior parent, maybe your own child, maybe a spouse, someone else in this moment — you also need to shore up your resources the best that you can so that you can provide all the care and support to others. So self-care is essential in getting through this experience.

Elizabeth DeStefano (33:34): So, Dr. Buse, we just talked about a point in time that may be earlier in the grief process — preparing for a funeral as an example. What about a little bit later in grief, as



someone is facing perhaps an anniversary of the loss, or maybe a first important or special holiday without their loved one?

Dr. Buse (33:56): That is a very good point, Elizabeth. And as the grief journey continues throughout a first year after a death of a loved one, there will be so many more times for the rest of that person's life that they might be reminded of their loved one who passed and hit with all sorts of emotions.

Dr. Buse (34:18): And a time that that can be really difficult could be around the first anniversary of a death or the first major milestones. It could be a first birthday of the deceased loved one or of the person who's bereaving. It could be a wedding anniversary. It could be a major event that that person's not there for — going to a wedding or a celebration or a graduation. Or it could be something very simple — driving by a favorite restaurant or seeing a picture pop up that brings back a flood of emotions.

Dr. Buse (34:55): So very much like someone engages in that gentle self-care early on in the process, there will be times when that person will again need to go back to that level of gentle self-care. They may want to do, again, some cocooning with comfort items on their own. Or, at that point, they may have found other support groups they want to reach out to — whether it's a friend, or a loved one, or an online support group, or someone in their community. They may want to reach out in advance to start talking about it and prepare.

Dr. Buse (35:34): It also may be that they either reached out for professional help and maybe they have a counselor. Or maybe it's time, if they're hit especially hard by these anniversaries, that they seek professional help to talk through the process. And we generally think of the, let's say, acute or early phase of grieving being up to the first year.

Dr. Buse (35:58): And if someone gets past those first-year milestones and is still very impacted by the grief — so much that it's hard to function in life — that's a good sign that it's a good idea to reach out to a professional counselor or psychologist. Maybe even talk to your primary care professional to assess how you're doing and think about referrals.

Elizabeth DeStefano (36:24): What types of signs might someone recognize that should encourage them to seek professional support and help in managing this complex, ongoing grief?

Dr. Buse (36:35): The first thing to keep in mind is that, along with bereavement, someone may feel high levels of depression and suicidality. And if someone feels like they may hurt themselves, that's an emergency. In that moment, they need to call a helpline or go to an emergency department. And there, they will get referrals and support for ongoing care.

Dr. Buse (37:01): For some people who are feeling not that level of distress, but still life has gotten very hard and they don't feel like they're functioning at the same level in the big areas of life — at work or school, with friends or family. Or if they've lost interest or pleasure in things that used to make them happy — and the term for that is anhedonia. If really nothing brings them joy anymore, that's a sign that there's some level of depression ongoing and it is worth seeking professional help.

Dr. Buse (37:36): There may also be a level of anxiety. The person may feel a heightened awareness. Perhaps the death was a traumatic death; perhaps it was an accident or an injury — something that someone might even have PTSD [post-traumatic stress disorder] from. Guilt — they might find that it plays over and over in their mind. We call that rumination. That is also a time to seek professional help. So any of those situations are worth talking to a healthcare professional. You can start with a primary care professional and they can help you find the right referral. Or you can go right to a psychologist, counselor, or support group.



Elizabeth DeStefano (38:18): Are there certain types of therapies that are best suited for this intersection of grief and chronic illness like migraine?

Dr. Buse (38:27): Yes. There are therapies, both individual therapies and group therapies, that have been developed to help people navigate bereavement.

Elizabeth DeStefano (38:37): One thing I'd like to acknowledge is that grief is isolating, right? Migraine is isolating. And the combination, as we've touched on, can be incredibly challenging — potentially devastating. How can a person, outside of their professional help situation, communicate to the people in their lives this double burden that they may be experiencing to get the support they truly need? What might be a simple script someone can use in communicating this effectively?

Dr. Buse (39:13): Well, one thing people with migraine often have already figured out is that there are people who understand and are supportive — and then maybe people in their life who are not as understanding and supportive. So finding your group is really important. And in migraine, we have the Migraine World Summit. We have some excellent online education and support groups offered by our big migraine organizations around the world. We have places to meet other people in the same boat who truly understand.

Dr. Buse (39:47): And for bereavement, those sorts of resources also exist. So first off, finding people who are more understanding, more accepting, more gentle, is a great place to start. When there are people in your life, in your world, that you need to interact with, and maybe they're not as understanding or gentle — maybe it's a family member, maybe it's someone at work, maybe a boss, maybe a coworker — then it becomes an act of sharing and disclosing what you want to share, and asking for the help or accommodations that would be helpful to you.

Dawn Buse (40:30): So when we think about a workplace, one of the safest places to start is with a human resources [HR] officer. And if you don't have someone in an HR department, it could be talking to a supervisor or boss about what you are going through — both the loss and the migraine — and figuring out what accommodations may be helpful.

Dr. Buse (40:51): And accommodations can be so wide ranging. It may be taking time off of work without the fear of loss of a job. And in the United States, that's the Family and Medical Leave Act — FMLA — that your headache doctor or a primary care doctor can help get in place for you. It may be allowing a more flexible work schedule, a hybrid work schedule, or maybe some work from home. It may be so many different things to each person.

Dr. Buse (41:20): But figuring out what accommodations might help you continue to do the things you want to or need to do — be it work or school, be it hobbies, or engaging in community. And so sharing as much as you're comfortable with so that people are aware of what you're going through, and then engaging to the level you're comfortable with, but also reminding people the same way that you do with migraine: "I'd like to commit to XYZ, but I may need to leave early, I may need to come late, or I may not be able to make it. And I just want to make sure you're OK with that so that we can have that understanding going forward."

Elizabeth DeStefano (42:01): Sounds like setting expectations and sharing what is comfortable are important parts, then, of communicating those needs.

Dr. Buse (42:08): I think those are always key to living well with any chronic condition or just being human. But in this case, those are really important. And always remember as well, a lot of people do want to help. They have good intentions, even if they don't know how to do it.

Dr. Buse (42:28): So go ahead and teach them how they can best help you, which might be offering something, doing something for you, listening — or might actually be nothing, just not asking about



it. And that's OK, too, to say, "For now, I'd prefer not to talk about it. And you can help me by honoring that." And of course, we will always get unsolicited advice that we don't want or need. So it's always good to practice these lines: "Thank you for that advice. I appreciate that you care. I am already working with an expert." Or: "Thank you for that advice. I know what I need. I appreciate that you care."

Elizabeth DeStefano (43:12): Great advice. We've been speaking in the context of someone who has experienced the loss of a loved one. What about for someone who is anticipating a major loss? Perhaps while caring for a loved one, or with someone they love who is elderly, or perhaps even their own death. Are there ways to prepare emotionally and physically to minimize the impact of migraine?

Dr. Buse (43:42): That's a time that can be filled with a lot of sadness and grief, as well as sweetness and joy. It's time to savor every moment, talk about what matters, and think about anything that you do want to say to people you care about while you still have that opportunity. This is also a good time to think about getting professional support. Depending on the particular situation, there might already be support available.

Dr. Buse (44:13): For example, if someone has a cancer diagnosis and they're late in their cancer journey, there may be social workers through the hospital or clinic. There may be also grief support groups already established that someone can reach out to find. Or, it may not be the case that there's already support in place, and you need to look for that — again, whether it's you who has the terminal diagnosis or someone you love.

Elizabeth DeStefano (44:43): To close, Dr. Buse, what is the single most important message of hope you would offer to someone who is currently in that fog of grief and migraine?

Dr. Buse (44:56): The bereavement journey is a long and painful journey. There's no right way to navigate it. Whatever you're feeling when you're feeling it is what you're feeling. And remember that grief is really the other side of the coin of love. And when you love deeply, you grieve deeply. It may be with you for the rest of your life. But at some point you may find that the balance of sad and painful feelings becomes a little bit more tempered with sweet and happy memories.

Dr. Buse (45:34): Of course, when you're navigating bereavement with migraine, you're laying two difficult things on top of each other. And so that kindness to yourself, the compassion, the self-care is always important. And those routines — even when you don't feel like doing them — know they are good for you. They're good for your body, good for your spirit to keep those healthy habits and routines. Above all, if you need support, it's out there. Reach out for support in whatever way feels right for you. Advocate for yourself in whatever way feels right for you. And know that what is right right now will probably change in the future — and that's OK. Above all, be kind and gentle to yourself.

Elizabeth DeStefano (46:24): Well, Dr. Buse, thank you so very much for the care and expertise you brought to this very important topic of managing grief and loss while living with a chronic condition like migraine. We appreciate you being here yet again on the Migraine World Summit. Where can those listening or watching learn a little bit more about you and the work that you do?

Dr. Buse (46:50): Thank you so much for allowing me to be part of the Migraine World Summit again, and thank you for including this really important topic that we probably don't talk about enough. A couple places you can find out more about me — I do have a website, which is just my name, dawnbuse.com, D-A-W-N-B-U-S-E dot com. On that website, I have guided visual imagery and relaxation exercises that someone might find comforting either when they're dealing with migraine or bereavement.



Dr. Buse (47:22): Also, if you want to find any of my research, it's all available on PubMed: P-U-B-M-E-D. And when you go to PubMed, you can just type in my name: “Buse,” B-U-S-E; and my initials, which are “D-C” — Dawn Carol — and see what I've been working on in research.

Elizabeth DeStefano (47:41): Dr. Buse, thank you so much for the care and expertise that you poured into this topic that's so important to our community in managing grief and loss while living with migraine.

Dr. Buse (47:53): Thank you again, Elizabeth, to you and the whole Migraine World Summit community. It is just a pleasure and honor to be part of this community.