

## **Creating Community while Protecting Privacy: What Should Thou Say?**

*by Claire Gorfinkel*

Like our biblical patriarch, “Abraham” was scheduled for surgery on an intimate part of his anatomy. Not wanting to endure inquiries about the subsequent functioning of his organs, he chose to keep his surgery secret from all but his immediate family. His partner sat alone in the hospital waiting room while the potentially life-altering surgery took place. He took a leave from work, and they were “too busy” for social engagements during his few months of recovery. Fortunately, the surgery was successful, and this couple has slipped back into the meeting community as smoothly as they slipped out – but without the support that caring Friends might have provided – and no one else undergoing a similar procedure will know to turn to “Abraham” to benefit from his experience.

Jacob, another of our patriarchs, never relinquished the dream of seeing his son Joseph again. Similarly, one of our members lovingly held out hope as he cared for his wife through the long years of her terminal illness. They and their children tried to remain actively engaged in first day school and meeting events, but he was shocked when another Friend, chatting with him in the parking lot, blurted out: “You know she’s going to die, don’t you?” After this and other thoughtless remarks, they let their membership lapse. The burden of illness was compounded, rather than eased, by the larger community, and conserving their emotional energy became a higher priority, or as he said, “Sometimes, one or two close friends are all a person can handle!”

“Dina” was a longtime member, a very private person, with a small circle of intimate friends. As she was dying, she withdrew into even greater solitude, rejecting offers of meals, visits, even telephone calls from those who had loved her. Her formerly close friends were deeply grieved not simply at her death, but especially at not being able to say goodbye to her, at not being able to console her or be consoled by her during her final days. One Friend mournfully asked, “Does dying excuse all behavior? Does illness and fear give someone the right to cut off our friendship or deny the broader community’s support?”

Then there was “Isaac,” another beloved member, who made a point of telling everyone about his early childhood trauma and every phase of his many medical journeys in later life. He gladly welcomed all offers of rides, meals, phone calls, and visits, and he reciprocated as much as he was able, until eventually some Friends began to turn away, feeling overwhelmed by the extent of his dependence.

I strongly believe that one of our most important human tasks is to create community – to engage with others in recreation, in common work, in spiritual and social events, in times

of sadness and in times of joy; to care for one another; to learn and to play together. I also know that we as humans truly love to help one another. We welcome being asked for small favors and large ones; we appreciate being needed. One of the many reasons we hold one another in the light, calling out the names of those in need of healing at the close of worship, is precisely because we want to help, and we want to know who might need help. We want to reach out to those who are sick and their caretakers: Can we send a card, make a phone call, offer a ride, or bring a meal? In coming together, especially in times of stress or sadness, we strengthen one another, and we strengthen our community.

Yet there are those in our community who don't want anyone to know when they are sick. They want control over when, if ever, others find out about an illness, whether it's potentially life-threatening, minor, or chronic. They don't want to be asked about their situation. Some diagnoses are more private than others, and some medical conditions (e.g., AIDS, mental illness, addiction) can lead to isolation, stigmatization, and/or negative consequences at meeting, school, or work. Some people find any attention intrusive. Some sense the need to marshal their own resources; they don't want to spend precious energy reassuring and "taking care of" other people. Some have been overwhelmed with unwanted advice from otherwise well-meaning people.

I absolutely want to respect each person's right to determine how they can best be cared for and by whom, and each person's right to privacy, but at the same time – and recognizing that no one strategy will be right for everyone – I want to raise questions about mutual responsibility and the role of community in our lives.

I can't know in advance how I will feel if and when I face a serious medical situation, but I do know that every time I have been with people who were ill or dying (even the opportunity to simply bring a meal or make a phone call), the interaction has informed both my head and my heart. I wonder how we can learn what it means to face illness and death if we do not go through those experiences with family members, friends, and our larger community. But not everyone needs to open their life to others; for some, it's no one else's business. Another might ask a small number of family members, or friends to hold their information in confidence. While our first obligation may be to respect an individual's desire for privacy, this may place a heavy burden on those who cannot express their concern and grief, for fear of divulging a secret.

And I wonder when it may be okay to say "no" when someone asks for assistance, or indeed when someone offers help. Each of us may need to learn how to gracefully acknowledge that while we might be the very best friend or caregiver for one person, there will be others for whom we're simply not the one they want to have around, and when they're ill or grieving, it's not about us!

What are we doing to build a meeting community that both cares for its members and feels well-cared-for, and how can we do better? We can begin by engaging in conversation about these questions, perhaps by introducing the four ancestors described at the beginning of this piece and inviting Friends to examine a time when they, or someone they knew, had a similar experience. What was their response? How might the experience have played out differently? What might they change in the future?

I would also like to suggest six principles, along with some questions, for further discussion. An adult education or worship-sharing session might tackle each of these areas at different sessions, or a meeting retreat might divide into six smaller groups, allowing each to reflect on one of the topics, and then bring their insights back to share with the others.

### **1. Autonomy**

*It is the prerogative of the ill or grieving person (and their immediate family) to determine how they wish to be cared for and by whom.*

What is our responsibility to those who wish to be left alone? How can we best respond when the burden of someone's neediness and their demands become overwhelming to the community? What is our responsibility to those who feel hurt by being excluded?

### **2. Hope**

*Hope is also the prerogative of those who are ill and their caregivers.*

We cannot overestimate the importance, to one who is ill and to those who are close to them, of holding out hope for recovery, or remission, or at least regaining strength for months, weeks, or even days. How can we ensure that our communications with those who are ill will be supportive? Is it always appropriate to be truthful?

### **3. Wisdom**

*The primary way to learn about illness and dying is by being with those who are experiencing them.*

For many people it is an honor and a gift to be allowed to help others, to share in their suffering, to offer the healing power of friendship and love. How can we help people feel comfortable asking for help? How can we help others overcome their reluctance to respond, for fear of saying or doing the wrong thing? Are there times when someone's desire to be of service becomes, instead, an intrusion?

### **4. Uncertainty**

*Life is unpredictable.*

Unexpected benefits may occur when we share our struggles and grief. And just as a routine medical checkup can yield a devastating diagnosis, and some individuals may outlive a dire prognosis for decades, similarly, important insights and wisdom may come from unexpected sources – even from intrusive people, rude remarks, and situations we don't like. Do we have an obligation to tell others when we're ill, overwhelmed, or grieving? How can we help our community remain open to the potential for growth and new insights even in the midst of health crises and pain?

## **5. Confidentiality**

*Keeping secrets is hard work.*

For some people, the risks of intrusive remarks and the burdens of consoling the would-be caregivers outweigh any potential benefits of having a supportive community. But silence has its costs, and once anyone knows some troubling information, she or he may need the comfort of sharing it. Is it ever appropriate to violate someone's confidentiality?

## **6. Compassion**

*Isolation, invisibility, and loneliness are routine facts of life for too many people.*

This is especially so for the elderly, the homebound and their caregivers, and for those who are single, whether by choice or not. Has someone's assertion of self-sufficiency or their request for "privacy" become a cover for self-pity or depression? Could we be doing more for the frail members of our community and to ensure that all are made welcome at our meeting events?

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