

The Day One Talk

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For the family of a child with cancer, the time of diagnosis is a time of emotional anguish. The formal discussion about the diagnosis and intended treatment frequently comes after a period of uncertainty. During this period, families are often acutely aware that cancer is the likely diagnosis, but the type of cancer, expected treatment, and likely outcome are initially unclear even to the physician. In addition, the child must often go through a series of uncomfortable tests and procedures. When the pediatric oncologist finally discusses the diagnosis and treatment with the family, fear about the news to come, combined with uncertainty, has created an anxiety that is difficult for the family to endure.

Because cancer in children is rare, few physicians will find themselves in the position we just described. But every physician will at times need to deliver bad news to patients, and the principles that apply to our specific scenario may be generalized to the care of other patients with serious illnesses. Previous reports have indicated that the initial communication of bad news can negatively [1-4] or positively [5] affect adjustment to the diagnosis. Recurrent themes in the literature include the need for a quiet and private physical setting [4-7], the importance of accurate information [3,4,8,9], the need for clear communication without either overly technical language or euphemisms [10], and the importance of letting the patient's or family's reaction guide the flow of conversation [5]. Families frequently note the physician's own emotional response [10,11] as one helpful aspect of the conversation that allowed for a sense of connection with the physician.

Beyond the impact of communication on coping and adjustment, the patients' understanding of their prognosis affects their choices for therapy [12], underscoring the need for physicians to communicate information about the natural history of the disease effectively and honestly. Similarly, in studies using hypothetical scenarios, patients' understanding of the burden of treatment and the likely outcome of treatment influenced their choices about therapies [13]. Yet even when the physician communicates with accuracy and compassion, the stress of receiving bad news may prevent a patient or family member from retaining information. For example, one third of parents of children with newly diagnosed cystic fibrosis felt they had understood and retained less than half of what their doctor told them [14]. These findings suggest that one essential aspect of delivering bad news is ensuring that the exchange of information among the patient, family, and physician will continue as the shock of the initial diagnosis fades.

Despite the importance of communication to the daily life of a physician, standards for education in this area have only recently started to emerge for medical students, with fewer established standards in residency and fellowship training [15]. Nevertheless, medical students and attending physicians alike can benefit from training in this area [16,17]. Although others [6,9,18,19] have reported on their personal approaches to delivering bad news, few guidelines exist for pediatricians or offer guidance about communicating with whole families. Here, we offer one method of delivering bad news to parents of children with cancer in hopes that our approach may be helpful to others and

may spur discussion. Our approach to this conversation, which we call the Day One Talk, has evolved through the collective experience of pediatric oncologists at a busy cancer center, in the care of hundreds of patients during the last 20 years. One of the lessons of this experience, however, has been the diversity of individual needs and preferences and the impossibility of finding one approach that works for every family. Inherent in any discussion should be a willingness to follow a family's lead.

As the physician readies to discuss the diagnosis of cancer with a new patient and family, the family's desire to have this conversation as soon as possible may impart a sense of urgency. Some amount of planning, however, facilitates a helpful discussion. A quiet location should be secured, and whenever possible, the physician should minimize the possibility of interruptions. The family should be notified of the time of the discussion so that they can arrange for important family members or friends to be present. We try to include nursing staff, psychosocial workers, and house staff whenever possible. In addition, for families who are not native English speakers, arrangements should be made for an interpreter, who also should be forewarned that this could be a long and painful discussion. Although the number of people involved may seem excessive, we find that once the conversation starts, this number almost never disrupts the connection between the physician and the family; in fact, it often feels like we, the physician and family members, are the only people in the room.

The decision of whether to include the pediatric patient is not always straightforward. However, we believe that teenagers should almost always be invited to attend. When adolescents are not part of the discussion, they may assume that the information they later receive is not completely honest and that the actual news about diagnosis and treatment is worse than what they are told. In addition, including teenagers from the beginning may help to engage them in their own care. In rare circumstances, an adolescent's developmental capacity may make participating in this conversation difficult. When this is the case, we ensure that a separate discussion with the adolescent is held. The purpose of the separate discussion is not to withhold information or to be dishonest, but rather to provide accurate information in a manner most comprehensible for the individual's developmental level.

The inclusion of younger children in the Day One Talk should be discussed with the parents; when children are not included, a separate conversation should be held with the child to discuss diagnosis and treatment. We would suggest that the physician deliver the news to the child in the presence of the parents. This takes the burden of delivering this news to the child away from the parents and ensures that the medical team knows what the child has been told. Role play of the discussion with the parents may be helpful if the parents remain uneasy about allowing the child to learn of the diagnosis. Families sometimes worry that news about

their diagnosis and needed treatment may be overwhelming for children to hear. We tell parents that the unknown is often more distressing than anything we have to say, and we think that open communication allows us to provide comfort and reassurance as well as help children know what to expect. In addition, all around the children may be indications of their diagnosis and its gravity, such as the sight of other children with cancer on the ward or in the clinic and the stress apparent on their parents' faces, and these signs may also contribute to worries for the children if the topic is not addressed openly.

At the very beginning of the Day One Talk, we start by asking the patient and family what their understanding of the child's illness is. This helps us to understand what we need to tell them and whether there are aspects of our news that are likely to be surprising, as well as whether there are misconceptions we should try to correct. In addition, this enables us to listen to the family with the goal of responding to their needs during this conversation.

We want families to hear and retain three things in the Day One Talk. The first major aspect is the diagnosis. Because attainment of a firm diagnosis often follows a period of uncertainty, telling families that we are certain of the diagnosis is important. When the diagnosis remains uncertain, the medical team should address this problem directly and acknowledge the family's potential frustration. This part of the discussion should include the word cancer to ensure that families understand that the child indeed has cancer, which allows them to confront the word. Some families fail to grasp that words like tumor or leukemia mean cancer and only later learn this from other families, staff, or even the signs at the cancer center. The word cancer has different meanings in different families, but for many families, loss is a part of their personal experience with cancer. We want to be able to help them to understand what cancer means for their child, and explicitly using this word in the initial discussion can help to connect the word with the information we are about to give.

The second major point of discussion is treatment and its goals. Often, for pediatric cancers, we have good treatment, and the goal of the treatment is cure. When cure is unlikely, however, or when the goal of the treatment is palliation, it is important to explain that also. Some patients and families will ask for specific numbers to suggest outcome at this point in the discussion. Asking parents if they are "number people" can sometimes help to understand their needs. Other families will be satisfied with words that convey a sense of the likelihood of cure [19]. In different circumstances, we may say things like, "We have very good treatment that cures most children with this type of cancer," or "There is a chance that we will be able to cure this type of cancer, but it will be hard," or "This type of cancer is almost impossible to cure." For parents who want numbers, it is important to explain what a cure rate means—that even with an 80% chance of cure, a patient can't be 80% cured; any one patient is either cured or not cured. What really

matters to the family is what happens to their child. For families who need a number to help frame this discussion and to gain some control over the sense of ongoing uncertainty about the future, we provide as accurate an assessment as possible.

The third major aspect of the discussion deals with causation. Many families seek meaning for this devastating event in their lives, and they may irrationally blame themselves for something over which they had no control [3]. We tell them that childhood cancer has few known causes and that we know of nothing that they or their child did or failed to do to cause the cancer. In rare cases where potential or partial causality exists (such as hereditary causes for a patient with neurofibromatosis and neurofibrosarcoma), we explain these issues directly. Parents also often wonder if a delay in diagnosis might have adversely affected treatment or prognosis. Generally, we are able to reassure parents that, although we cannot say when the cancer started or when it would be expected to spread, the parents and pediatrician responded appropriately to the child's symptoms, and we have no reason to believe that the diagnosis should or could have been made sooner. In cases where we know there has been a delay, we acknowledge that fact. Although no one is able to predict if a child's outcome would have been any different if the cancer had been found sooner, it is important to acknowledge the sadness and fear associated with the situation. If the patient is not present for this part of the discussion, we talk with the child in a later discussion about the fact that he is not to blame for getting cancer because oftentimes the child has this question as well.

At this point, the discussion can turn to the facts that the family needs to know before treatment begins. The cancer should be described with discussion about where it begins, how it can spread, and what we know about whether the tumor has spread to other parts of the body. The consent form can be introduced, and a copy can be given to the parents as a guide for the discussion about treatment. We use a written consent form or drug information sheets for all patients, whether or not a research protocol is used. This allows an avenue for referral later, after much of the Day One Talk is forgotten. If there are many possible choices for treatment, or if the proposed treatment is a research protocol, this should be explained to parents, as should the specifics of the questions to be addressed in the research protocol and its available alternatives. Previous research regarding informed consent has shown a lack of understanding among parents of pediatric cancer patients concerning issues of participating in clinical trials [20]. In particular, parents infrequently understand that the purpose of research is to benefit future patients rather than to benefit their own child. This issue should be addressed with each family who considers participation in a clinical trial to ensure informed decision making.

Treatment can be discussed in general terms with an emphasis on the phases of treatment (eg, induction and local control) and the impact on the child's life at the

various phases (eg, time in the hospital or as an outpatient and time of return to school). Asking about the child's and family's prior experience with cancer and cancer treatment can help us to understand pre-existing knowledge or misconceptions. Side effects of chemotherapy can be discussed first, in general, with an emphasis on common side effects, such as myelosuppression and hair loss, followed by a more specific discussion of the agents intended. Before reviewing a long list of many possible side effects of the prescribed chemotherapeutic agents, we tell families that everyone gets some side effects but that no one gets all the possible side effects. As we review possible side effects, we point out which side effects we expect and which we think are unlikely.

Once the consent form has been discussed, many families feel exhausted by the amount of information they have been given coupled with the emotional tension of the days preceding diagnosis. At this point, we try to acknowledge the enormity of this event in their lives. We tell them that we know their lives have been changed forever by having a child diagnosed with cancer. Even so, the parents and child are fundamentally the same people as before, with all the joys and sorrows that exist outside the current crisis. We let them know that other families have told us that, with time, this fundamental dichotomy becomes easier to handle. In addition, we tell them that family members and friends may treat them differently; some will avoid them, and others will want to talk with them all the time. Although this is a horrible time to ask them to be forgiving of others, with time, relationships too will get easier. Friends and family members will learn that they are the same people, though forever changed.

At this time, too, we often address the inconvenience of cancer. Although this may seem a strange topic of discussion at the time of diagnosis, families will find over time how difficult it is to plan their lives. This is a frustrating aspect of cancer treatment, and families may appreciate having some forewarning or some acknowledgment of the inconvenience they may have already experienced.

Many families will have already sought information about cancer on the Internet or from family or friends even before this discussion takes place. We discuss resources available to them, such as physicians, nurses, social workers, psychologists, and materials about cancer and its treatment that we can provide. In addition, we address outside sources, such as material available on the Internet, in the lay press, and from family members of other patients. We tell them that all cancer is not the same and that what they find, read, or hear may have no bearing directly on their child's cancer. Therefore, we encourage them to talk to us about outside information so that we can help them place it in perspective. Families of other patients, in particular, can be a huge source of support. Still, we remind parents that what happens to other children will not necessarily happen to their child.

Finally, we tell parents that they are now part of a team. Our role in the team is to teach them about their child's disease

and to plan and supervise the treatment. Their role is to teach us about their child and themselves because this will help us to provide better care. We remind the families that we will be with them for as long as their child or they need us.

We then close the discussion by reiterating the first three points. The volume of information they receive in this discussion can be overwhelming, and we tell them that we do not expect them to remember everything. We ask them instead to remember that we know the diagnosis, that we have treatment for it, and that the cancer is neither their child's nor their fault.

Separate discussions with children should include many aspects of the conversation with their parents. We try to have conversations even with very young children, and we let their reactions and questions guide the depth of the discussion. We usually suggest that parents and other important people in their lives be present but that we do the talking. We always tell children that we know the diagnosis and use the word cancer. We tell them that we have treatment for it; even young children often understand our words when we tell them that we will give them medicine (or other treatment) for their tumor with the goal of making it go away forever (and/or of making them feel better). We describe the treatment in terms that we think are important to them, such as how long they are expected to be in the hospital, whether they will feel tired or sick, when they will be expected to return to school, and whether they will lose their hair. For children who are likely to lose their hair, we talk about when we expect this to happen and whether we expect it to come back when the treatment is done. We tell them that, although they are likely to sometimes feel sick as a result of their treatment, we will work to help them feel better. We also let them know that we count on them to let us know what doesn't feel good or what isn't going well, so that we can work to make those things better; the children are a very important part of our team. We tell them that the cancer is not their fault

and not their parents' fault. Finally, we tell children that we will answer their questions honestly and do everything possible to help them through this time.

Our description of this encounter emphasizes the words of the physician. But often, we find that the heart of the encounter is not in what the physician says but in the patient's and family's response. Because the emotional impact of hearing this news may make understanding of the medical details difficult, it may not be possible for the physician to follow a specific agenda with transmission of large amounts of information. Early in the conversation, it can be helpful to acknowledge how hard the news is and to give the family the opportunity to respond. Careful listening, assessment of their understanding, and a willingness to be flexible about the content of the conversation can help the physician to respond to the individual needs of the family. The factors that contribute to the creation of a connection between a patient, family, and physician are intangible, but listening and the openness of silence may be more important than the words themselves [21].

Every physician must at times give patients bad news. This duty may be one of the most stressful aspects of a physician's job. And yet, these interactions may provide some of the most meaningful moments of a doctor's career. Although seldom emphasized in medical school, conversation is a major, and sometimes the only, way for physicians to alleviate suffering. In addition, this beginning to the therapeutic relationship often teaches us most clearly what is extraordinary about our patients and their families.

Authors' Disclosures of Potential Conflicts of Interest

The authors indicated no potential conflicts of interest.

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