# A Parent's Second Greatest Gift

**As more states reform guardianship laws to account for medical advances that are prolonging the lives of the terminally ill, single parents are giving their children the most important gift next to the miracle of life itself: security in the event of the parent's death.**

by Jason Howard

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A wrinkle of worry is etched across "Ally's" forehead as she steers her car over to the curb. Turning to face her 8-year old son, "Nick," she knows that this may be the most important conversation they will ever share.

"Nick, I have a question," she says softly. "Not to scare you, but I'd just like to know what you'd like done if anything was to happen to me, God forbid. Who would you want to take care of you?" Ally sees the look of confusion on Nick's face and reaches across the console to pat his hand. "Don't be scared, honey. I just need to know, would you want to live with your grandma and grandpa or your dad?"

"I'd go with you," he says.

"But what if I was in heaven, and you couldn't?" she asks gently.

What comes next nearly tears her heart in two. "I'd go with you," he repeats. "I'd come build a house next to your grave."

Gulping back a quiet sob, Ally pulls Nick close. "Honey, that's not an option," she tells him with a kiss. "Who would you want to stay with? Would it be Daddy or Grandma and Grandpa?"

"I'd go with Grandma," Nick says after a moment of thought. "I'd want to live with Grandma."

Nick is still too young to know that this is more than just a hypothetical conversation. It will be a few more years before Ally will have another conversation like this with him, this time to tell him that she is HIV-positive. In a nation that is sometimes uncomfortable initiating a frank dialogue on death, terminally ill parents such as Ally are asking themselves the question that no parent wants to contemplate: "Who will take care of my child when I'm gone?" They are then taking the critical steps necessary to ensure that the legal system understands and hopefully will honor their wishes when they're gone. In finding answers, these parents are giving their children what may be the most important gift next to the miracle of life itself: security in the event of the parent's death.

Historically, states have offered limited options for parents in Ally's situation. They can opt to designate a legal guardian in their wills, or they can transfer parental rights through an adoption or guardianship prior to their death. However, in recent years, the legal issues surrounding a custodial parent's right to choose a future caregiver have become more complex. Medical advances have prolonged the lives of many living with terminal illnesses, especially those infected with HIV. New antiretroviral drug therapies have given new hope to single mothers like Ally. However, their uncertain life spans, punctuated by intermittent periods of sickness and good health, have complicated traditional legal arrangements that determine who will take custody of the children and when.

These developments have led to the emergence of a new permanency planning tool known as a "standby guardianship." Standby guardianship laws allow custodial parents to make future care plans that don't take effect until circumstances require. While statutory specifics vary from state to state, the intent of these laws is to enable parents to grant temporary custody to a person of their choosing when they become seriously ill. In other words, the custodial parent is putting the chosen guardian on "standby." In the event they recover, custody reverts to the parent. If they die, custody passes to the predetermined guardian with court approval.

"During periods of hospitalization, parents may need someone to legally take care of their kids while maintaining a way to transfer legal rights back to them should they get well," says John Krall, a policy analyst with the National Abandoned Infants Assistance Resource Center (NAIARC) housed at the University of California at Berkeley. "There are concerns that a parent's will is sometimes not honored by the courts. The idea here is that a parent can go to court in advance to explain to a judge the reasoning behind a decision and get a standing order issued as to who will assume custody when the time comes."

Ally wanted to make sure there was no ambiguity about who would care for Nick if her HIV develops into full-blown AIDS. She felt it was important for a judge to know that Nick's father has been absent from his son's life since the court awarded her sole custody in the divorce. "I've worked very hard to get my son where he is, and I know that my ex-husband isn't capable of raising him when I'm gone," she says.

Her concerns about Nick's future care are justified, since many judges are predisposed to award custody to a biological parent in the absence of compelling evidence that it would not be in the child's best interests, Krall says. "Biological parents have rights. One of the reasons behind standby guardianships is to give sick parents a chance to explain the circumstances to a judge and tell the court why they would prefer a different guardian. Often, it's because the other parent has not been there for the child, while there are other family members out there who have."

## PLANNING AHEAD

As a low-wage worker at a publishing company in the midst of a messy divorce, Ally could not afford a lawyer to advise her on custody and future planning issues. "My ex-husband told me that he was going to go to court to tell them I had AIDS, and he was going to take my son away from me," she remembers. "That just set everything into motion for me. I panicked."

The New York City Department of Health referred her to Safe Space, a nonprofit organization that provides counseling and other help to at-risk families. Ally attended an HIV counseling session, where her counselor told her about Queens Legal Services' HIV Advocacy Project. Her panic began to melt after meeting Project Director Lisa Isaacs, a knowledgeable and compassionate advocate who was eager to help.

Isaacs says many clients in Ally's situation initially seek out legal aid for counseling with housing or estate planning issues. Often, they are experiencing great stress because of some estrangement or family conflict. "We'll see someone in a housing crisis, for example, and notice that there are minor children involved," Isaacs says. "Then we'll go from there and discuss whether there are any issues that need to be addressed through a standby designation. Very often our clients say to us, 'Well, that's a great idea.'"

After helping Ally secure sole custody of Nick, Isaacs suggested that she consider designating a standby guardian for him. The decision was one she would have to face essentially alone. The ongoing absence of Nick's father in his life, she felt, indicated that he would be unfit to assume parental duties, so she turned to two people whom she knew were qualified to raise a child in a loving and supportive home: her parents.

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"Planning forces a parent to ask, 'What are my options for who would care for my children?' and then to actually go speak to those people," says Cathy Bowman, director of the HIV Project at LSC-funded South Brooklyn Legal Services. "Doing the legal groundwork also leads to doing a lot of emotional groundwork because families are forced to really start talking to each other, to work through problems and address what they want."

After discussions with her parents and her heart-wrenching talk with Nick in the car, Ally was confident she had made the right decision. She opted for a written designation that would go into effect in the event of one of four triggering events—mental incapacity, physical debilitation requiring consent, consent itself, or death. In any of those eventualities, Nick's grandparents would automatically assume legal guardianship for 60 days, after which they could petition for permanent guardianship. The document designating them as standby guardians would be presented as irrefutable evidence of Ally's intent. Should her condition improve, she would reassume her parental rights.

Written designations like Ally's are more common than going to court to make guardianship arrangements, Isaacs says, noting that most HIV-positive clients want to avoid lengthy and potentially contentious court hearings. Parents with terminal diseases, she notes, want to maximize their remaining time with their loved ones. Isaacs believes that many HIV-positive parents prefer a written standby designation because they do not want to make their HIV status an issue in the court proceedings. Those who choose to go the court-appointed route, she says, are typically those diagnosed with late-stage cancer or AIDS.

"People's life expectancies have been significantly extended," Bowman says. "So a lot of people are not really prepared to use the court-appointed standby guardianship. Sometimes it causes complications for them, because you ask the judge to appoint somebody, and then the parent stays healthy for 10 years. There can be a lot of changes during that time, including a parent's choice for a guardian."

In cases where there is a history of spousal conflict or an absent parent, such as Nick's father, Isaacs recommends that her clients include a statement about the other parent. "We'll very often write into our standby designation a comment: 'In no event do I wish [name of parent] to be the guardian because…' Then we will describe why—they are abusive, they don't pay their taxes, *et cetera*," Isaacs says. "That doesn't bind a court, but it at least encourages a judge to inquire into areas that have been identified as problems, and they usually will side with the client."

Bowman says that the more conflict her clients anticipate on the issue of future custody, the more she encourages them to appear before a judge to make the case as to why their standby designation should be honored. After an initial hearing, Bowles says, courts will conduct compulsory investigations and, in most cases, approve the appointment.

"I say to people all the time, 'If you think you know how people in your family are going to act, you're mistaken,'" Bowman says. "Everybody comes out of the woodwork and does crazy things after somebody dies, as anybody who has ever worked with trust estates can tell you." For situations where there is a history of family conflicts, Bowman advises her clients to go straight to court to name a standby guardian.

Today, in a quiet voice accented with the sense of relief that her new legal arrangements have provided, Ally recalls those dreadful, uncertain days following her initial diagnosis and how, in her darkest hour, legal aid was the light. "When I felt like there was no help out there for me, when I felt like every door was being closed, they actually opened doors for me," she says. "I didn't know how to figure everything out, didn't know how to make it happen. Lisa and her staff made it happen."

## APPROACHES VARY BY STATE

According to the Family Center, a nonprofit organization dedicated to permanency planning for children, more than 60,000 children in New York City have lost a parent to a terminal illness—more than enough kids to fill Yankee Stadium. Statistics like these prompted New York lawmakers to become among the first to pass a standby guardianship statute in 1992. The law has evolved over the years to be increasingly sympathetic to the seriously ill custodial parent, including granting the option to designate a standby guardian in writing.

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Currently, 22 states and the District of Columbia have passed some form of standby guardianship law according to the Family Ties Project, a Washington D.C.-based program that helps families affected by HIV/AIDS make decisions about the future care of their children. The laws can vary significantly by state. For instance, California's "joint guardianship" statute requires court approval in all instances. California's version allows parents to choose a joint caregiver to share custody during the parent's sickness and assume parental rights upon death.

"It doesn't mean that the parent has lost the right to have a say in the child's life. A classic example we see is on days of medical treatment for parents with HIV or AIDS, the joint guardian can give permission for medical procedures for the kid," explains Dan Grunfeld, President of the Los Angeles-based Public Counsel Law Center, a nonprofit organization that last year helped 6,300 children with a range of legal issues through its Children's Rights Project. The Project's unique Peace of Mind Program recruits and trains volunteer lawyers to help terminally ill parents select a joint guardian. The lawyer then represents the parent in family court to make the most compelling legal case possible in support of the parent's choice.

Peace of Mind's holistic approach then goes a step further. Public Counsel employs a team of social workers who encourage the joint guardian to

bond with the child while the parent is still alive. At the time of the parent's passing, the social workers offer grief counseling to the children. Ensuring a successful transition to the new guardian can be central to a child's long-term emotional health, Grunfeld says.

"They feel like they're being abandoned," he says. "Part of it is an emotional reaction, and in some cases it is an objectively correct view: that's exactly what might happen if something is not done to provide for their future care. When children have somebody in their lives already who they love and respect, whom they know by first name and can hug and hold hands and go to a ballgame with, the process becomes more emotionally manageable."

In 1997, Congress passed the Adoption and Safe Families Act, which states, in pertinent part, "It is the sense of Congress that the states should have in effect laws and procedures that permit any parent who is chronically ill or near death, without surrendering parental rights, to designate a standby guardian for the parents' minor child." Yet 28 states have enacted no such laws, causing considerable consternation for advocates in those jurisdictions.

"There is no viable mechanism [in Kentucky] for parents to plan for the care of their children during times of intermittent or temporary incapacity," says Eileen Ordover, director of the HIV/AIDS Legal Project run by the LSC-funded Legal Aid Society in Louisville, Ky. "The only option short of adoption or termination of parental rights when they're in one of those periods of illness is to petition to have a guardian appointed at a time when they are not in the best mental, physical, and emotional state to be doing that. Then, when they come out of that state, they have to go back to court to petition to have the guardianship lifted."

The cumbersome process that Ordover describes is precisely what standby guardianship laws seek to avoid, says South Brooklyn advocate Bowman. "If a plan hasn't been made, it leaves the future care of the children up in the air. That means, ultimately, the situation is going to have to be litigated without the most important party present: the caretaking parent," she says. "As a result, a lot of other resources might have to be expended by agencies investigating the situation. Kids get bumped around, which is obviously not good for them, and it also puts a lot of economic pressure on the system because kids end up in foster care. That is obviously much more expensive than children being raised by their families."

Grunfeld emphatically agrees: "As we all know, it's best if kids—if they have other viable choices—do not end up in the foster care system. This is a very compelling and powerful tool in making sure that does not happen."

As for Ally, her experience with permanency planning has reinforced for her the reality that time is a luxury not afforded to people in equal portions. The security she has found in making a solid plan for her son's future has enabled her to focus on fighting the disease. After an initial setback involving harsh side effects from her antiretroviral drugs, she now has found a combination therapy that is successfully fighting off the HIV. Ally has reached what she calls a "comfortable point" in her life, cherishing her friends, her career, and most of all, Nick. She cheers him on at all of his swim meets and his basketball games, savoring each moment. She doesn't know how much time she has left, but she knows Nick will always be loved by someone she trusts.

"In my situation—in *anyone's* situation—you never know what's possible," Ally says. "My whole life changed when I was diagnosed. I knew I had to live for my son. I looked deep in myself and said, 'I'm not going to allow this to take me. I'm going to fight back.' Now, I've been given peace of mind knowing that my son will be taken care of should anything happen to me. It makes it a whole lot easier for me not to worry and stress about the future." ■