

# Chapter 2

## A Donor by Coincidence or by Conception – *My Sister’s Keeper* Revisited



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**Abstract** Thirteen-year-old Anna Fitzgerald has been conceived in order to be a matching donor for her older sister Kate, who has a rare form of leukaemia. The story in the novel “My Sister’s Keeper” by Jody Picoult, and Nick Cassavetes’ movie, has many striking similarities to the situations that we heard from the families we studied – despite one significant difference: Anna is created to be a saviour sibling, whereas the stem cell donors we interviewed already existed and were found to be matching. We discuss the film as an emotionally complex, multi-layered narrative that gives insight into the perspectives of different family members and into some key aspects of a paradigmatic family conflict. The temporal order of the film’s story-telling using multiple flash-backs and retakes represents the entangled temporalities of experience and memory.

**Keywords** Film · Movies · Bioethics in movies · Saviour siblings · Organ donation · Bone marrow transplantation · Child · Child’s well-being · Family narrative

Campbell Alexander: Well, no one can force you to donate if you don’t want to, can they?

Anna Fitzgerald: They think they can. I’m under 18, they’re my legal guardians.

Campbell Alexander: They can’t do that.

Anna Fitzgerald: Well, that’s I want you to tell them, because they’ve been doing it to me my whole life. I wouldn’t even be alive if Kate wasn’t sick. I’m a designer baby. I was made in a dish to be spare parts for Kate.<sup>1</sup>

The novel and the movie *My Sister’s Keeper* (Picoult 2004; Cassavetes 2009) tell the heart-wrenching story of Anna Fitzgerald, a 13-year-old girl who was conceived to be a bone-marrow match for her older sister Kate, who suffers from a rare form

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<sup>1</sup>Scene from the movie, at minute 7.

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of leukaemia. This story is a showcase for the bioethical question: Should it be permissible to conceive a child using pre-implantation genetic diagnosis and selection for the purpose of generating body parts to treat a sibling with cancer?<sup>2</sup> But it is also so much more: an exemplar of family dynamics associated with sickness and treatment of one child in a family, and the possibility for one other sibling to help out with stem cells from her or his own body. All family members are affected, and so are their relationships. But how they are affected and the moral position they take are the issues unfolded as the story develops.

In the story, Kate had been diagnosed with acute promyelocytic leukaemia (APL) at the age of two and desperately needed a stem cell transplant. Her brother was not a match, and nor were the parents, and no unrelated donor of hematopoietic stem cells could be found. Chances to save Kate's life were fading, so the parents decided to use a novel and dramatic biotechnological procedure: pre-implantation genetic selection to find an embryo who would be a perfect match for Kate. A matching embryo is then chosen: Anna. However, blood stem cells from her umbilical cord do not work, so leukocytes, lymphocytes and bone marrow are taken from her as a little child. But Kate's cancer recurs, and her sister Anna is finally expected to donate one of her kidneys. In this situation she chooses to sue her parents for the rights to her own body. Campbell Alexander is her lawyer, representing her in court and supporting her against her parents' plan to use her as a kidney donor.

The story depicts the struggle all the members of the Fitzgerald family face, especially Anna's battle between loyalty to her dying sister and her rights to her own body (Bonk 2008; Elfarrar 2018). However, it consistently avoids the individualistic stereotype of "leave me alone, my body is my own". In a surprise turn towards the end of the movie and book, we learn that Anna does not defend her individual rights to her own body *against Kate's* needs but acts in solidarity with Kate's own wishes to end being trapped in a horrific clinical odyssey that has become increasingly troublesome and burdening for her.

Superimposed on the tension between altruistic donation and the right to one's own body in this story is the conflict between two different aspects of care. One aspect is represented by the mother Sara, who organizes the family in order to obtain the stem cells as a remedy for Kate. The other is represented by Anna, who knows about Kate's deeply felt therapeutic fatigue and unwillingness to undergo further surgery. This makes the movie and the novel especially relevant and interesting for the topic of our book – despite the difference that the families in our Lübeck study did *not* conceive their donor children by IVF and did *not* select an embryo by pre-implantation genetic selection. The donors in our study were children who had already been born and *became donors by coincidence*, first, because they were a sibling and second, because their inherited HLA pattern happened to be identical to the patient.

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<sup>2</sup>Vandenhouten and Groessl (2014); Trifolis (2014); Prendergast (2008). The reception of the film was also sensitive to the topic of "saviour siblings", a practice that is allowed in Israel but banned in Germany (see Raz et al. 2017). For a discussion of the ethical issues of saviour siblings see Rehmann-Sutter and Schües (2015).

## 2.1 Inspirations for a Multi-layered Narrative

The title “My Sister’s Keeper”, used for both the novel<sup>3</sup> and the movie after the book is certainly a biblical allusion to Genesis 4:9 – the story of Cain and Abel. We see, however, that this narrative reference does not play any role in either the novel or the film. It is a catchphrase that makes the story recognizable (and perhaps helps to sell the book and the movie). But it indicates a completely different context – a drama of jealousy, murder and guilt that is far removed from the contents of Anna Fitzgerald’s story. We remember what is at the centre of this biblical text: after having murdered his brother, Cain is questioned by the Lord: “Where *is* Abel, your brother?” He then replies with a blatant lie: “I do not know,” adding a remarkable counter-question: “*Am* I my brother’s keeper?”<sup>4</sup> Cain’s answer is evasive, and, given his acts and the situation, outright scandalous. The Lord was of course aware of what had happened (“The voice of your brother’s blood cries out to me from the ground” Gen 4:10) and banishes Cain to a life of wandering. He protects Cain against revenge and violence by setting a mark upon him so that whoever found him will not slay him. Cain then dwells in the land of Nod, builds the city Enoch, and his wife and he have children.

In *My Sister’s Keeper* we learn that Anna Fitzgerald rejects being her sister’s keeper, by refusing to donate her kidney and by enforcing her decision in court. Despite this, Anna is her sister’s keeper in daily life, but in a way that is resolved rather late in the film, She is her closest confidante and ally who helps her to carry through her wishes within the family. Conceptually, Anna was conceived in order to be a stem cell donor for Kate. In contrast to Cain, who was Abel’s older brother, Anna was the younger sister, born with the plan to be a keeper and saviour for Kate. For Anna, this was a heavy burden that made it even more difficult to exercise her own will. By refusing to be a kidney donor, she would not only become responsible for Kate’s death but would also counteract her parents’ benevolent plans. She is charged with guilt herself, but would also face being viewed as guilty by others. Does she want to have a future life where others see her as a person whose body is a remedy for her sister? Is the duty to donate inscribed into her body, into her person (Schües 2017)?

There are two inspirations for Picoult’s story that are more pertinent. (i) In an interview Picoult discloses a personal experience behind the novel: her youngest son Jake had a tumour in his left ear. It was benign; however, “it can get to the brain and kill you... so you’ve got to get rid of it. We took an experimental approach that required multiple surgeries” — 13 of them. “Had we used a more traditional approach, Jake would have been profoundly deaf.”<sup>5</sup> Having accompanied the 5-year-old child through many operations, Picoult realized how much she was willing to do for her boy, even though he was not in a life-threatening situation. But the questions

<sup>3</sup>The German translation runs with the title “Beim Leben meiner Schwester”, thus losing the biblical allusion.

<sup>4</sup>New King James Version.

<sup>5</sup><https://www.jodipicoult.com/my-sisters-keeper.html> (last visited on 27 Oct. 2020).

about what it means to be a good parent, a good sister, and a good person stayed with her. Taken to the extreme, she took one question to be the guiding theme of the book: Is it morally correct to do whatever it takes to save a child's life?

From this experience she learned that it was not only Jake who was touched by the diagnosis and the treatments. The whole family was affected and its dynamics changed – by the diagnosis, the anxiety, the complicated surgeries, the sudden overwhelming importance of medicine for family life, the care relationships and so forth. “When one child gets sick, the whole family does.” (Picoult 2015) As she explains, this experience provided her with a narrative perspective for writing the novel about Anna and Kate as well. She tried to tell the story from the point of view of all family members, not only the patient's and the donor's perspectives, but that of the other family members as well.

(ii) Following on from this question, she took further inspiration from a real case, which was highly publicized in the USA at the time: the story of the Nash family (Faison 2005; Hendrickson 2017). Lisa and Jack Nash found themselves at the mercy of a controversial medical procedure to save the life of their daughter Molly, who had Fanconi anaemia. They conceived Adam by IVF and PGD, to avoid the Fanconi gene and also to be able to use cord blood from the placenta. Adam Nash was born in 2000 to treat 6-year-old Molly. The media referred to him as the first “designer baby” (Franklin and Roberts 2006).

The Nash family certainly found this international media hype, with the implied questioning of their morality, difficult to endure. And Picoult's story did not intend to do justice to the Nashes. Besides, Molly could be treated without taking cells from Adam's body. For the situation of the family this certainly makes a big difference. Other complications that were much more burdening for Adam and Molly, such as long-term dependence on tube feeding, are specific to Fanconi and do not appear in Picoult's scenario. In comparison with this real-life example, the novel and film both use the means of dramaturgic exaggeration, in order to highlight a dilemma: not only cord blood was donated, but also bone marrow, leukocytes and lymphocytes, and finally Anna was asked for a kidney. The novel (in contrast to the movie) has even a more dramatic turn at the end, when Anna's lawyer Campbell Alexander, driving with Anna after their success in court, is involved in a severe car crash. Anna is declared brain dead and becomes a postmortem kidney donor for Kate. In this respect Picoult's scenario does not attempt to be realistic, although representing one not very probable but still *possible escalation* (and complication) of the course of events.

Anna and Kate's story is in the centre of the play. They question each other and help each other to make sense of the events. The Nashes' story provides a real-world reference and shows how far people would go even when the situation is not about survival. The bioethical debates that were conducted in their names provide a background of moral questions. The author's own son Jake's story provides a whole-family perspective on the illness and treatment of one child. All family members are affected by the child's sickness, and throughout the treatment their emotional involvement changes. The multi-layered narrative is a method for Picoult as an author to show different dimensions of meanings manifest in the family; it is

therefore also a method of analysis for us as interpreters. Like the family in the film, the families in the interviews we conducted, where the members talked openly and listened to each other, also relied on a multi-layered narrative in order to understand difficult situations. The different perspectives can be used as examples that can be compared and evaluated for the given situation. The interviewees tried to make sense of and find their own story by way of other stories they knew. Or they used a collective imaginary, for instance that of the “lottery” where you can win, or of the “hero” or “saviour”. Using such images and narrative tropes that seemed to be meaningful for them, interviewees tried to identify themselves and other family members with certain roles and situated the family in a complex relationality that is not in one individual’s hands.

In the analysis below, we refer to the film version of *My Sister’s Keeper*, directed by Nick Cassavetes (USA 2009). It closely follows the plot of the novel – with one important exception, as already mentioned: the ending with the car crash and the postmortem kidney donation is left out. The movie ends with Kate’s mother Sara finally accepting that a kidney transplant cannot happen. In the horizon where Kate and Anna have had their desires, Sara learns that she needs to let her daughter go.

## 2.2 Dynamic Family Perspectives

Focusing on the movie’s description of the changes in family dynamics unleashed by Kate’s illness and its treatment, we can distinguish three main phases.

The first phase – told in brief flashbacks, mainly in the words of mother Sara – starts with Kate becoming ill and ends with the birth of Anna. Little Kate is diagnosed with a rare form of leukaemia: this changes everything in the family. Kate’s cancer is a threat to her life. The Fitzgeralds and Kate’s physicians try everything possible to fight this disease but the chances fade away. Soon her only option would be a transplant of stem cells that could rebuild her damaged immune system. However, her parents and brother Jesse are not an HLA match and are therefore unable to donate. Kate’s oncologist (Dr Chance) tells the parents Sara and Brian that there is one ultimate possibility, innovative but not illegal: to have another child and to make sure that it will be a 100% HLA match and a donor for cord blood. Sara immediately takes this up (Sara: “We got to do it, we got to try” Min. 14). Bearing another child is something Sara *can* do. It is in her power. With the support of modern biotechnology, the birth of this child will create an opportunity to generate healing cells for Kate. The only procedure they have talked about is using the blood from the umbilical cord, something Anna would not need once she is born, and that would otherwise be discarded.

In the second phase, Sara is the organizer of everything in the family, trying to create the best possible situation for the medical support of Kate. Both parents, however, love Anna and her elder brother Jesse as well.

The cells from the umbilical cord are used but they cannot hold back the cancer for long. They try with lymphocytes taken from Anna’s blood when Anna is 5 years

old, and then one year later, granulocytes, again from Anna's blood. And then a bone marrow transplant. After the bone marrow aspiration there is a complication and Anna has to be hospitalized for 6 days.

Later, doubts arise. At one point, father Brian recalls the scene when he had to hold Anna, a desperately crying, kicking and struggling little girl, down on the operating table using his whole body power until she was sedated: "Have we really pushed her too hard? ... She was so little when all this started" (Min. 19). Brian, a firefighter by profession, is not as intellectual as Sara, who is a lawyer. He supports all the necessary decisions to fight for Kate's life but has a better and more balanced sense of the different feelings, needs and desires. He often just watches his children without saying much, resonating with his children's feelings. Picoult gave him the profession of a fireman and the interest in astronomy. A fireman is there to help people in a state of crisis and destruction, while astronomy is there for a scientific understanding of the positions, movements and characteristics of objects, stars, matter and radiation in the universe. A reference to Immanuel Kant's saying might help us to understand the role of the father: "Two things fill the mind with ever new and increasing admiration and reverence, the more frequently and persistently one's meditation deals with them: the starry sky above me and the moral law within me." (Kant 2002, 203) It is Brian's role to explore the moral constellations and to link them with the particular situation and position of one person. He realizes that the family is at risk of falling apart if only one perspective and one driving force prevails. Sara is the one who has such active driving force, at least in this phase of the story.

Sara's conviction that she can and must somehow save her older daughter leads her into a presumptuous attitude that she fails to ask or notice what either of her daughters actually want. Anna is regarded as a bodily remedy for her sister and a sacrifice for her mother's refusal to withdraw from her path of opting for the removal of Anna's kidney. Removing a kidney, Anna knows, is a serious operation that has long-lasting effect.

On an emotional level, Sara's care for her endangered child goes so far as to help Kate to get out of a depressive phase (Kate: "I am sick and I am tired and I am ugly" (Min. 22)) by shaving her own hair in order to look like Kate with a bald head. It works and the family has some more happy moments. Later, when Kate realizes that her end is near, she talks openly with Dr. Chance about palliative care options. Seeing that, Sara shouts at Kate: "Listen. I don't want to hear talk like that, okay, honey. You just stay strong enough for surgery!" (Min. 38). She is in denial of the situation and keeps believing that a kidney transplant could save Kate – with Anna as the donor, of course.

In this phase of the family dynamic, Jesse goes more and more off the rails. He starts having problems at school and is sent away from the family for a whole year to a special school to learn maths, a decision he accepts in tears, understanding that it is a necessary sacrifice. He plays a desperate role in the story, setting fire to things, and even watching the crises from afar and knowing that his father is part of the crew battling the flames that he has caused. Unable to help, and not being given any attention himself, he becomes involved with fire for creation and destruction, for

despair and reason. Kate sees this and is sorry to have taken all the attention when Jesse needed it most (Kate: “They barely even noticed that Jesse was dyslexic” Min. 25). Nevertheless Jesse loves Kate; at one point he brings her a beautiful watercolour portrait of her that he has painted.

At the point when it is decided that she should donate her kidney, Anna starts to act on her own. She refuses to be a donor (“I don’t want to do it any more, Mom” Min. 15). This action of Anna’s turns the plot around. She now becomes the protagonist of the story, as she introduced herself right at the beginning of the film as “a designer baby” (Min. 7) who wants to sue her parents because they want to make her a kidney donor against her will. She finds a well-known lawyer (Campbell Alexander) with an advertised “91% success rate” in court, and mandates him as guardian *ad litem* to sue her parents for her right to refuse a live organ donation, which involves a limited termination of parental rights.

This move by Anna – the start of a third phase in the family drama – creates an additional tension for the other family members and also for the film audience: How could the 11-year-old Anna, who loves Kate so much, refuse to donate and sue her parents for her personal rights to decide about her own body? One part of her motif is easily understandable: she does need her own kidney, and she has suffered enough already (8 hospitalizations in 11 years, 6 catheterizations, 2 bone marrow aspirations, 2 stem cell purgations, and the necessary accompanying drugs with their side effects, as Campbell Alexander enumerates them in his plea). She does not want to “be careful” in her life and she wants to have children herself, all of which could be problematic with only one kidney. But is that sufficient to explain her emphatic demand and her willingness to stand for her rights in court – against her parents?

In the same period Kate’s health deteriorates; she realizes that she is going to die (Kate: “I am ok with it. ... I don’t mind my disease killing me. But it’s killing my family too” Min. 24). It is also the time of Kate’s love story with the fellow terminal cancer patient Taylor, which revives her. After some intimate moments, when they run away from the prom party, Taylor dies and leaves Kate devastated.

Jesse’s situation deteriorates as well. He is often seen on the streets in town. Once when he misses the last bus and comes home late in the middle of the night, he tells the audience off-screen, in a narrator’s position: “When I got home, I wondered how much trouble I’d been in” (Min. 60). Dad was still up – not worrying about Jesse not yet being at home but because of worrying about Kate. He realizes how far out of his parents’ main considerations he is.

The couple Sara and Brian as parents increasingly run into difficulties in their relationship. At one point, when Brian, with support of Dr. Chance, wants to take Kate out of hospital to the beach close to where they live, in order to let her see the Pacific for one last time with Anna and Jesse, Sara shouts: “You are killing her!” He yells: “I want a divorce!” (Min. 65). However, the situation brightens up again after Sara gives way and joins them on the beach, together with her sister Kelly. She sees how Kate enjoys the happy moment in the roar of the ocean waves and the sun. Facing the present moment makes a difference, and again Sara’s sister and friend Kelly acts as counsellor, telling her that she does not see the big picture: “Sooner or later, you got to stop. You got to let go” (Min. 62).

During this third phase the family becomes most disconnected, close to breaking point. Brother Jesse comes back into the centre of attention, and of reasoning, when in court he breaks the secret that Kate had asked Anna to refuse to donate her kidney because she, Kate, did not want to go on with the surgeries (Kate said to Anna, asking her to refuse to donate: “You can release me” Min. 82).

Compared to Jesse, Anna, the child born to be a saviour, seems not to be at the weakest end of the family. Campbell Alexander asks Dr. Chance in court: “Can you tell us one single benefit that Anna has received from any of these procedures?” Dr. Chance replies: “Yes, she got to save her sister’s life” (Min. 71). Jesse lacks this. His task is to live off the little remaining attention that he can get from his parents, to endure the family crisis without being able to really help, while growing up himself, and not to lose ground during his difficult years. Sara’s care for Kate, which takes somewhat extreme forms, is challenged by the other siblings’ needs and by her love for all of them. But often she is unable to see these needs at all. At some point she even loses sight of Kate herself as a person, while fighting for her life using all that medicine can offer – against Kate’s own struggle and willingness to accept dying, and in this sense, against her family as a whole.

### 2.3 Entangled Temporalities

The film ends on a sentimental chord. Anna, again resuming her role as main narrator, explains that she does not know why Kate had to die while she, Anna, could live. After Kate is gone, the memories of her are vivid and, as Anna says, “our relationship continues” (Min. 98).

It is noteworthy to see how the film is cut and composed to tell its story and how the multiple narrative layers are intertwined. The film has been criticized for having too many flashbacks that follow emotions and lose sight of reality (Bradshaw 2009). We, however, can see some good sense in this formal choice. There is not a single chronological line that leads through the film. The only part of the story told in chronological order is the court procedure. It extends from the beginning, when the audience hears (from Anna herself as narrator) that Anna is about to sue her parents, to the last minutes of the movie, when Campbell Alexander visits Anna to bring her the documents about the success they finally had in court. The court scenes, the scenes in the lawyer’s office, in the office of Judge de Salvo, the judge’s visit to Kate in the hospital, and the court sessions themselves are spread throughout the movie – in a straightforward chronological order.

However, the medical procedures, as well as the family stories and the story about Anna and Jesse, are organized by showing flashbacks and by visualising a memory. The family story, and also Kate’s story as the patient, are composed of singular stories from different times, partly in the present and partly in the past, filling that present with meanings and depth. They assemble as a *Gestalt* that is temporally construed by moving slowly forward, pulling the characters acting within it, sometimes driving, sometimes being driven by the entangled components of this



structure, towards the point of decision about the desperate last attempt of a kidney transplant or palliative care.

How much the memory of earlier viewings of this film can straighten out these temporal curls and wrinkles that make up the screen experience of it! Despite having seen the film at least three or four times, and having used it in academic teaching some years ago, we were both surprised when revisiting the film after a few years for the preparation of this chapter. We remembered the story of Kate and Anna as a much more straight-line story, while the film actually presents it with innumerable temporal folds. This is much closer to how memories are built up while living through difficult situations (Ricoeur 2004).

If this is true, the superposition of temporal layers is also closer to the experiences of the families in our study who have lived through a time of severe illness, care and responsibility. The experience of a slowly but relentlessly forward-moving *Gestalt* of activities and passivities, of decision-making while always remembering and being at the mercy of one's emotions, can be seen as a cinematographic attempt to capture the complex temporal structure of this long-term experience of severe illness and of hope for rescue, of finding the right way forward in a situation that is neither obvious nor morally clear. The film attempts to capture the manifold perspectives that are held by the individual family members. They cannot be interchanged because each person has an existential position based on their particular way of bodily being and their medical, social and familial role within the setting.

## 2.4 What Can We Learn?

The book and the film have different endings, yet the complexity of the situation remains. In a very convincing way the film gives each person his or her own voice to express concerns or feelings, judgments or values. On a superficial level, we learn that each difficult constellation has more perspectives to it. Since all these different perspectives are uttered in the familial context, the members are challenged to try to understand each other's perspectives. That this is not always easy comes as no surprise. On a deeper level, we can learn that not only is each dimension – the juridical, ethical, familial or medical – controversial, but there may also be tensions between them that cannot be resolved easily.

However, if one aspect is decided in one dimension it will immediately have consequences for another, e.g. allowing children to ask for the help from an attorney can even result in the judge's decision to grant the freedom of decision in medical matters (that children usually do not have). Thus, we may learn that the care for a child's well-being in the medical sphere of difficult decision-making (as we have seen with stem cell transplants) should also include an attorney who juridically consults with the child and who may protect her from the unwarranted demands of parents or doctors.

The film (and the book) grants an insight into a complex moral setting. If we viewed it as just a moral setting, we would reduce it to an unfounded moral dilemma.

However, if such a moral setting is seen as a juridical, ethical, familial, medical and temporal setting, then there may be a chance to deal with this situation in a way that later admits, retrospectively, that the decisions and the actions were undertaken in an appropriate way (Schües and Rehmann-Sutter 2014). A morally difficult situation is always temporally situated and challenged by the power of time. The medical decision often has to be taken “now”; there is no time for deliberation or consultation with each other. The temporal entanglement of the family members does not end with a decision, but provides a framework to prospectively and retrospectively care and carry responsibility for the family and its members – the parents and the children. Nonetheless, a book or a film would not be a piece of fiction mirroring insight into reality without using metaphors, exaggerations, clues and hints to guide the viewer on the path of concern for the ties of a family.

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