

# Down's Syndrome: Informing the Parents Guidelines with a Jewish Perspective

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## INTRODUCTION

There has been extensive discussion of counseling practices at the birth of a child with Down's Syndrome. Such discussions and studies are especially needed in view of changes which have occurred in the past decade. Our society has seen a new emphasis on increased education and increased socialization as well as increased medical prognosis for persons with Down's syndrome.<sup>1</sup>

Early intervention and increased educational opportunities have resulted in greatly increased mental capacity.<sup>2,3</sup> Today the average child with Down's syndrome develops an intelligence quotient in the mildly or moderately retarded range.<sup>3</sup> A physician can affect the development of an infant by the timing and the manner in which he tells the parents of the diagnosis.

These factors are generally more important than the physician believes. His counseling might determine whether the child will benefit from the opportunities now available to Down's syndrome children. Unless the physician is aware of current developments and new approaches to counseling, it is understandable that his advice to the parents might be outdated.

Down's syndrome is unique among hereditary defects. It involves mainly mental rather than physical defect. It is recognizable by a physician at birth, and yet it is not obvious to all mothers.<sup>4</sup> Other birth defects, such as cleft lip or spinal bifida, are impossible to conceal from a mother. The physician does not have the option of deciding when the mother should be told. She sees the defect as soon as she is shown the baby. Down's syndrome, on the other hand, will not necessarily be detected by the mother. This provides the physician with the opportunity of delaying disclosure. Guidelines are needed for the timing and manner of this crucial diagnosis.

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Serious counseling deficiencies are still reported by parents who have experienced the birth of a child with Down's syndrome. Counseling suggestions have been repeatedly made. However, they are seldom taught in residency programs.<sup>5</sup>

Several examples illustrate the problem:

- In 1976 many physicians used the term "mongolism" when introducing the diagnosis to the parents. Some even used the term "mongoloid idiot," a term which is both degrading to the child and insulting to the parents. A parent surely reacts differently to a child termed an "idiot" than to one described as having Down's syndrome.<sup>6</sup>
- As recently as 1984 a physician broke the news to the parents by asking, "Have you ever noticed anything funny about the baby?"<sup>7</sup>
- Recent studies have reported delays of up to six months before a physician discussed the diagnosis with the parents.<sup>1</sup>
- Physician's advice has been based on outdated and false information. For example, some physicians assume that 95% of the children with Down's syndrome are severely retarded. Others gave no advice other than telling the parents that sterilization should be considered early in the child's life.<sup>1</sup>
- Most shocking is a 1982 court case concerning a decision made by the physician and parents to allow a Down's syndrome child with tracheoesophageal anomaly to die from starvation. The court justified the decision after being told that "a minimally acceptable quality of life was not present in a child with Down's syndrome."

## WHEN TO INFORM THE PARENTS

Down's syndrome is the only common mental defect which is recognizable at birth by the physician, although it is not obvious to the parents. There have been two schools of thought as to when to inform the parents of their child's condition. Since neither the diagnosis nor the prognosis is in doubt, some have held that the parents have the right to be

informed at once or as soon as the mother has recovered from the immediate effects of delivery.<sup>8</sup> Others have maintained that there is no virtue in telling the parents immediately. These claim that acceptance of the handicapped child and adjustment to the fact of mental defect is facilitated if the parents are left in ignorance in the early months. In this way the mother can form a normal loving attachment to her baby. Further, the mother needs some time to recuperate after delivery. Therefore, distressing news should be withheld from her.<sup>9</sup>

Parental experiences and preferences support the latter view. In a 1970 study 11% of the mothers interviewed would have preferred delayed disclosure. One mother stated

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that she needed more time "to pull herself together." Three felt they could have had a further period of happiness with their babies had they been informed later. Yet another felt "it might have come along easier if it dawned on you slowly."<sup>4</sup>

There are disadvantages in delaying disclosure. Several parents said they found it extremely difficult to tell other people their child had Down's syndrome after initially having indicated that the baby was fine. It is essential

that the mother not suspect anything wrong with her child. Delaying disclosure therefore requires a well trained hospital staff.

Several cases illustrate the difficulty of concealing the diagnosis from the parents:

- A mother suspected something abnormal because many medical students seemed especially interested in her baby.<sup>10</sup>
- Some mothers suspected a problem because the special kindness shown to their babies by the medical staff.<sup>10,4</sup>
- By chance, another mother glanced at her child's case notes.<sup>10</sup>

Once suspicion of abnormality arises in a mother's mind, it grows quickly. This leads to anxiety and the diagnosis must be disclosed.<sup>11</sup> Mishandling of this situation has occurred in a number of hospitals. Mothers who expressed to the medical staff suspicion of a problem with their babies were either falsely reassured or were told lies: "As soon as she was handed over to me she didn't look right. I asked the nurses and they said: Oh, all babies look like that."<sup>4</sup>

Lying is perhaps the worst aspect of delaying disclosure. Discovery of the diagnosis from an inappropriate source or in a distorted manner, or lies by the physician undermine the trust relationship. This point alone justifies telling the parents immediately. Parents have a right to all available information concerning their newborn child. A physician withholding this information denies them this basic right and causes a loss of confidence in all parents of newborn infants.

It follows that if a policy of delaying disclosure is adopted, one must guarantee that the parents not suspect anything wrong. For two reasons this is not always possible.

First, medical personnel cannot always avoid arousing the mother's suspicion.<sup>10,4</sup> Second, increased public awareness of many medical matters lead many parents to suspect something wrong from the baby's appearance and behavior. The number of mothers who suspect a problem with their Down's syndrome newborns is rising. The longer the delay in forming the parents, the greater the risk of discovery by the parents.

The disadvantages of delay outweigh the advantages. The assumption that delay in disclosure of the diagnosis is necessary for bonding of mother and child is questionable. Delay in disclosure may not facilitate acceptance of the child by the parents. It may even impair the chances of acceptance. Parents who suspect something wrong and who are fobbed off by their physician might reject their child because of the delay. They might think that the diagnosis was concealed because of its severity. Recent studies suggest that delay is not the solution to improve bonding. Giving the parents honest and factual information as soon as possible does improve bonding.<sup>12</sup> Parents prefer immediate disclosure. According to recent studies 90% of parents prefer to be told during the first week.<sup>11</sup>

In summary, the physician should tell the parents of the diagnosis as soon as possible. Further study is needed to determine just how early. The only justifiable reason to delay disclosure beyond the day of birth is the state of the mother's health. In any case, she should be told within the first week and before being discharged from the hospital. Under no circumstances should one lie to the parents if they ask about their child's condition.

## WHO SHOULD TELL

Hospital policy should determine who is to notify the parents. Should it be the obstetrician? Or should it be a pediatrician? A 1976 study reported cases of parents who left the hospital presuming their child to be normal and were only later notified of the diagnosis by mail.<sup>4</sup> A 1984 study reported a case in which a mother was given a letter for her general practitioner when discharged. She opened the letter and a neighbor explained to her what Down's syndrome meant. Other mothers were informed by the hospital registrar. Often medical students broke the news to the parents.<sup>7</sup> It is clear that a set policy is needed to determine who is to notify the parents.

A 1974 study found that parents definitely prefer being informed by a physician. But this study does not suggest any preference for either the pediatrician or obstetrician.<sup>11</sup>

Some parents preferred the obstetrician for the following reasons:

- The obstetrician is usually the first to see the baby. "He is the first one to know and I want to be told immediately."<sup>11</sup>
- A mother giving birth to her first child might not have

met the pediatrician. The obstetrician, on the other hand, has followed her pregnancy and is the most trusted physician to the family.<sup>1,6</sup> "It was my first child and he was the only doctor I knew."<sup>11</sup>

There are also reasons for preferring the pediatrician:

- The pediatrician is the best informed and most knowledgeable about Down's syndrome. "He is the doctor who really knows about children."<sup>11</sup>
- The pediatrician is the physician who will treat the child. "He is the doctor I'll be coming back to for follow-up visits."<sup>11</sup>

It seems that the optimal solution would be for the obstetrician and pediatrician to tell the parents together. Many researchers support this opinion.<sup>1,6,11</sup>

Others have suggested that a team consisting of obstetrician, pediatrician and social worker inform the parents. This introduces a specialist knowledgeable in aspects of family dynamics, adjustments in stress situations and available resources in the community.<sup>6</sup>

The team must be available to the parents as soon as possible to avoid inappropriate forms of disclosure. If the team is unavailable, there should always be a physician authorized to respond if the mother asks of the normalcy of her child. Subsequently the team can be sent to the parents to offer advice and further information.

## HOW SHOULD PARENTS BE TOLD

A 1974 study reported that only 24% of the parents were informed together, although 86% felt they should have been together when told.<sup>11</sup> More recently, a 1984 study reported that 74.6% of the parents were told together.

There are many reasons for informing the parents together. It is more difficult for one parent to bear the stressful load alone.<sup>6</sup> It is a problem which the parents must face together.<sup>11</sup> Each parent can offer the other emotional support.

It is also important to establish the proper terminology to use for the diagnosis. In a 1976 study, 65% of the physicians used the term "mongolism," 16% used the term "retarded," and only 15% used the term "Down's syndrome." Four percent of the physicians used other terms including "slow muscular development," "something wrong with glands," "brain-damage," and "hydrocephalus." In five cases the child was referred to as "mongoloid idiot."<sup>11</sup>

Success in counseling is in part dependant on choosing the right term. "Mongolism" conjures up unfortunate stereotypes and has a negative connotation. The physician should use the term "Down's syndrome" and tell the parents that some people might use other terms such as mongolism.

In this way the parents are made familiar with the terminology ("mongolism"). But it should be emphasized that their child is first looked upon as a human being with characteristics apart from stereotypes.<sup>6</sup>

In one model procedure the physician begins by saying: "Hello, I am Dr. X, the baby specialist. I have been

examining your baby and have found several features which suggest that he is probably what we call a Down's baby. Do you know what that is? [Pause.] It is what used to be called a mongol baby."

How the telling is done is more important than who does the telling. In general, the parents that spoke appreciatively of the way in which they were told were those who felt that the physician was "sympathetic, took trouble over the explanation and answered their questions fully."

Parents spoke resentfully about physicians who seemed "cold and unfeeling" or who told them abruptly and then dismissed them. "He carried on writing all the time he was telling me."<sup>4</sup>

Many parents reported a long series of frustrating attempts to obtain information on Down's syndrome. They complained that physicians overly emphasized the negative aspects of their child's condition. Some parents reported that physicians overly emphasized the positive joys of raising a child with Down's syndrome and the great blessing such a child should be to the family. Others complained that the physician failed to mention that almost every child with Down's syndrome suffers from some form of medical problem (hearing loss, speech difficulty, constipation, etc.) which continues after fears of neonatal problems have passed.<sup>1</sup>

It is important to understand the psychodynamics of parental responses. Parents should be expected to express emotional distress when told. Acute anxiety, desperation, disbelief, and confusion are seen in the shocked parents. This stage of emotional disorganization is followed by the process of reintegration when psychological defense mechanisms become increasingly mobilized. Later, during mature adaptation, most parents are best able to face the presenting realities.<sup>6</sup> By awareness of this basic procedure, sensitive guidance and support the physician can bring about the family's realistic adjustment to the situation.

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While in initial shock, the parents cannot fully grasp the physician's explanations. He should not overwhelm the parents with information. Instead, the parents should have continuing access to the physician for counseling as crises develop and feelings grow. These later contacts should be aimed to develop family support for the child and an understanding of reasonable goals.

In summary, the physician should familiarize himself with the needs of each family prior to the initial counseling session. He should be aware of the psychological processes they will experience. He should tell the facts sympathetically and offer support. The infant should be held by the physician to enhance positive feelings at the time of disclosure. The physician should answer the parent's questions honestly. He should be available for further questions. A follow-up session after recovery from initial shock should deal with expectations for the future and referral to a local child development center. Without subsequent support and guidance, counseling will fail in its main objective of ensuring an optimal future for the child.

In the past physicians often recommended institutionalization of children with Down's syndrome. In an attempt to protect the family, many physicians told parents that their child would never be able to do anything since it was profoundly retarded; they said that the child would be a menace and a destructive force within the family and would have a negative influence on its siblings.<sup>11</sup> All this is incorrect.<sup>6</sup>

Immediate institutionalization has a profound and lasting negative effect on the child's development. Today, few physicians recommend it.<sup>6</sup> Many parents comment that institutionalization would deprive them of the joy, enrichment, and satisfaction they experienced in rearing their child in their own home. The suggestion of institutionalization might lead the parents to abandon their child in the hospital and interrupt the natural bonding between parent and child.

### MODEL FOR INFORMING THE PARENTS<sup>7</sup>

- The parents should be informed as soon as the mother's health allows, no later than one week after birth.
- A pediatrician and obstetrician should present the diagnosis together.
- The parents should be told together.
- The baby should be held by the pediatrician during the initial counseling session.
- The session should be in private with no other persons present.
- The physician should tell the facts directly, but in a sympathetic manner.
- The physician should use the term "Down's syndrome" and avoid such outdated terms as "mongoloid" or "idiot."
- It is improper to counsel the parents to avoid becoming attached to the newborn.
- It is improper to suggest institutionalization.
- The physician should allow and answer questions.
- The parents need a place to be in private with each other after disclosure.
- The physician should make an appointment for a follow-up session and allow the parents free access for questions.
- The parents should receive literature about Down's syndrome and information concerning local referral centers and parental support groups.

### HALACHIC PERSPECTIVES

The proposed procedure is based largely on parental preferences and suggestions. It directs the physician to permit bonding between parent and child and consequently preclude institutionalization on the infant. This raises a number of ethical questions.

What are the parents obligations towards their child? Should institutionalization be avoided in every case? Should

counseling be mandatory for the physician or should he avoid counseling the parents?

The views presented here are a general survey of the issues as found in halachic sources, not final decisions of *halachah le-ma'aseh*.

In the Bible there is no commandment obligating a father to feed, clothe, or care for his child. There is indeed a commandment to bring forth children, but the responsibility of the father after the child's birth is unclear in Scripture.

In the Oral Law there is a principle that certain properties, qualities, values and traits in human nature precede Torah (דרך ארץ קדמה לתורה). These aspects of human nature are the essence of proper conduct (דרך ארץ), and if human nature would lack these aspects, Torah would be unable to continue to exist. In Tractate Kethuboth there is a case of a father who refused to maintain his young children:<sup>15</sup> "Turn a mortar for him upside down in public. Let one stand on it and say: The raven cares for its young, but that man does not care for his children!"

A raven, which is not noted for piety, cares for its young; this is elementary in nature. The Torah, therefore, did not need to assign a specific commandment for caring for one's child. The Torah takes into account the qualities that are part of human nature and relies on them.<sup>16,17</sup>

The Sages did not rely on human nature alone. They legislated laws, known as the Takkanot of Usha, concerning home and family life. According to the Talmud: At Usha it was ordained that a man must maintain his sons and daughters while they are young.<sup>15</sup> The great poverty that prevailed after the Bar Kockba revolt necessitated for the legislation of this law.

Before explaining the law, we must remember that the basis of the obligation is naturally embedded in every parent. The law merely defines the extent of the halachic obligation.

There are a number of issues to be clarified. Until what age is the father obligated to provide for his child? If he refuses to comply with the law, how may he be compelled or punished? If there is no textual source for the law in Scripture, what is the legal basis for the law as promulgated by the Sages?

Rashba states that a father who refuses to maintain his child up to sixteen years of age may be forced by a rabbinic court to care for his child. Rashba reasons that a father must support a child only when that child has no means to support himself. But if the child has resources of his own, "why should the father be obligated to maintain him?"<sup>18</sup>

Maharam of Rothenburg disagrees. He holds that a father must support even a child which has resources of its own (e.g. an inheritance from his mother's family).<sup>19</sup>

Rabbi Perl explains that the difference of opinion between the two earlier authorities is rooted in different understanding of the essence of the laws of Usha.<sup>17</sup>

Maharam of Rothenburg understands the laws to be social in nature and, like all laws involving property, are based on the principle that the court can impose financial obligations (הפקר בית-דין). These laws were made to protect children from certain abnormal phenomena in human

nature. Therefore, even if a child has the means to support himself, the Sages obligated the father to support him. Thus they hoped to eliminate such abnormal behaviour from society.

The rabbinic court was entrusted with the power to force the father to care for his children and thus, educate him to normal moral behaviour.

Rashba, on the other hand, held that the laws of Usha were based on the principles of charity. Therefore, the rabbinic courts can force a father to support his child only when that child has no other means of support. If the child has his own resources, he is no longer considered a poor person, and the rabbinic courts have no power to force the father to care for the child.<sup>17</sup>

The view of Maharam of Rothenburg was adopted by the Shulchan Aruch.<sup>16</sup> The law is not one of charity, but is a financial obligation binding the father in a very concrete way. Thus the father must support his newborn and may not place the obligation of support on the public.

The manner in which the physician informs the parents of his diagnosis is crucial to the future of the child and will therefore have an impact on the fulfillment of these legal principles. The physician can allow a loving attachment to occur, leading parents to take their child home. Or he can give priority to the parents' and siblings' needs, neglecting the child and causing institutionalization at public expense.

In terms of Jewish law, the physician should do everything in his power to assist the parents in fulfilling their obligation. He should prevent the abandonment of the child in the hospital and the concomitant burden on the public.

The Mishna deals with the case of a difficult pregnancy. If the pregnancy threatens the life of the mother, one aborts the fetus "because her life takes precedence over its life."<sup>21</sup> The principle that the mother's right to life is superior to that of the fetus is valid until the moment of birth. Then, after the delivery of the fetus's head, its life is of equal value to that of the mother; one may not set aside one life for another.

Rabbi Feldman commented on this principle as follows:<sup>22</sup> This doctrine, by the way, has very interesting implications for the whole question of wantedness and quality of life, recognizing a difference between the mother, who has a husband and other children and associations, and the child, who has none of these. But the child does have life, and once the child has human life, then it is equal to that of the mother with all her associations, with her husband and children depending upon her. It follows that the societal status of the neonate in Jewish ethics is one of equality; one life is not more important than another.

Once born, Jewish law regards every child as being worthy of the Next World.<sup>23</sup> This applies equally to normal and to physically or mentally handicapped children. Dr. Avraham wrote in the name of the Gaon of Vilna: How great and pure is the soul of a fool, who's sole purpose for existence in this world is to perfect and complete his soul and how great is the privilege of the parents who allow him to do so.<sup>24</sup>

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Like any other patient, the neonate should theoretically have the right to participate in medical decision making. This right must by necessity be extended to a guardian or surrogate. Traditionally, the family is the surrogate or guardian.

Rabbi Tendler questions this practice for a number of reasons. First, the family is not always a friendly, unbiased surrogate.<sup>25</sup> A leading pediatric surgeon wrote: "Physicians are often confronted with parents refusing to give permission for surgery [in a case of a baby with Down's syndrome born with duodenal atresia] saying that if the baby has an obstruction and will die without the surgery, the death would be a blessing for the baby as well as for the family."<sup>26</sup>

Second, family members cannot always make intelligent decisions. Often the private concerns of parents conflict with the rights of the infant. Considerations of financial expense and psychological stress on parents are often the dominant forces in this decision-making process, not the rights of the infant. Parents in such situations often neglect their obligation towards the child.<sup>25</sup>

Rabbi Tendler suggests requiring a trained team of medically informed ethicists, assisted by the family, to make such decisions.

Judaism places stringent restrictions on disclosure of confidential information.<sup>30</sup> The prohibition against divulging personal information is derived from the biblical verse "Thou shalt not go as a bearer of tales among your people (Leviticus 19:10)."

Rambam writes:<sup>27</sup>

Who is a tale bearer? One who carries... reports and goes from one person to another and says, "So and so said this or such and such have I heard about so and so." Even if he tells the truth, the tale bearer destroys the world.

Nonetheless, there are cases where professional confidences must be revealed.<sup>28,29</sup> In cases where the patient will benefit from disclosure, the physician is permitted to break the confidence. It seems, therefore, that the physician is only permitted to disclose the diagnosis to the parents for the infant's benefit. Thus he should do so in a manner which will allow attachment, encourage the parents to take the infant home, etc.

Rabbi Bleich refers to an early source which discusses the disclosure of medical information for the benefit of persons other than the patient.<sup>30</sup> Hafetz Chaim holds that medical information dealing with the health of a prospective marriage partner may be divulged. Disclosure is restricted in the following ways:<sup>31</sup>

- (1) One may disclose the presence of a disorder or physical defect.
- (2) One may not exaggerate in any way.
- (3) The sole motivation for disclosure must be the benefit of the person to whom the information is being given.
- (4) Disclosure is permitted only when there is reason to

believe that the information will be a determining factor in the contemplated marriage.

Rabbi Bleich quotes Rabbi Breisch as holding that it is obligatory to reveal information designed to avert personal tragedy or financial loss.<sup>32</sup> According to Rambam and the Shulchan Aruch, disclosure under these circumstances is mandated by the biblical commandment: "You shall not stand idly by the blood of your fellow man (Leviticus 19:16)."<sup>28,29</sup>

According to Hafetz Chaim, disclosure is mandated to preserve property as well as to preserve life. Rabbi Bleich argues that there is another commandment applicable in these cases: "Thou shalt not place a stumbling block before the blind (Leviticus 19:14)." The Sages understand this as prohibiting a person from giving detrimental advice in all matters.<sup>33</sup>

In general, advice intended to bring unhappiness or financial loss is forbidden. On the other hand, a physician may not remain silent in cases which would end in grief or loss to others.

The disclosure of Down's syndrome to the parents is in many ways similar to the case of disclosure to a prospective marriage partner. In both cases the person informed will be living with the affected party for his whole life. In both cases the person being informed will have to care for the affected party.

Although the physician must disclose his diagnosis, he must do so in an acceptable way. No exaggeration is permitted ("idiot," "menace," etc.). The physician must be objective and, if he has biased feelings about Down's syndrome infants, he must refer the counseling to a physician free of such feelings.

The physician's counseling should lead the parents to take their baby home from the hospital. He must not hide any fact concerning the child and should show the positive aspects. In this way the physician allows the parents to care for their child and provide for him in the best possible atmosphere: the home.

Later, if necessary, the physician may suggest the option of institutionalization. But first he must assure that the parents take their child home. This will result from the procedures outlined above and will foster a positive nurturing family environment for the infant and minimize parental complaints about the counseling process.

It is unreasonable to think that any set presentation of the diagnosis will ever be met with appreciation and gratitude by parents who have been looking forward to the birth of their baby. However, we hope that parents, physicians, and rabbis will continue their efforts to educate each other in the medical and religious values and needs concerning this sensitive situation.

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