



# BMJ Open Support needs around the time of diagnosis of parents caring for an infant with visual impairment or blindness in Denmark: a qualitative study

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## ABSTRACT

**Objective** The whole family is affected when an infant is diagnosed with visual impairment or blindness. We aimed to describe the support needs of parents around the time of diagnosis.

**Design** We used a descriptive qualitative method based on the theory of critical psychology and conducted five semistructured interviews with a total of eight parents of children under the age of 2 years who had been diagnosed with blindness or visual impairment before the age of 1 year. Thematic analysis was used to extract primary themes.

**Setting** The study was initiated by a tertiary hospital centre specialised in the ophthalmic management of children and adults with visual impairment.

**Participants** Eight parents representing five families caring for a child under the age of 2 years with visual impairment or blindness participated in the study.

The parents were recruited from the Department of Ophthalmology at Rigshospitalet, Denmark in relation to appointments in the clinic or by phone or email.

**Results** We identified three themes: (1) recognition and reactions during the time of diagnosis; (2) family, network and struggles; and (3) interaction with healthcare professionals.

**Conclusion** The main lesson for healthcare professionals is to bring hope at a time when all hope may seem to be lost. Second, a need to direct attention to families with no or sparse supportive networks. Third, coordinating appointments between hospital departments and at-home therapies and reducing the number of appointments to allow parents time to establish a family relation with their child. Parents respond well to competent healthcare professionals who keep them informed and who see their child as an individual rather than as a diagnosis.

## INTRODUCTION

All members of the family are affected when an infant is diagnosed with visual impairment or blindness, and the responsibility for the course of the disease and the subsequent rehabilitation process becomes a substantial part of the family's everyday life.<sup>1 2</sup> In general, parents of children with a profound impairment or disability face significant challenges around the time of diagnosis.<sup>3 4</sup> The

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ We used qualitative interviews, which allowed us to gain in-depth insight.
- ⇒ We conducted a thematic analysis to condense the essential findings.
- ⇒ The result of this study offers transferability to other settings; however, limitations concerning generalisability must be considered due to the sample size of the study.

diagnosis is a milestone, which, in many aspects, outlines the prognosis of the disease. Transitioning to being a parent of an infant with a visual impairment or blindness can cause significant stress as parents negotiate the many challenges associated with caring for their child, and the implications of the impairment or disability for their child and family.<sup>5</sup> It is therefore essential that the parents receive support and help around the time of diagnosis.

In Denmark, children <18 years of age are registered in the Danish Registry for the Blind and Partially Sighted Children when the child is diagnosed with a visual impairment defined as visual acuity 0.3 ( $\leq 6/18$ ) or significant visual field defect. In addition, children with a hereditary and progressive retinal eye disease are included in the registry irrespective of their visual function at the time of diagnosis. The most important function of the registry is to ensure that the children receive the help needed to be able to manage at home, in school or at an institution. After registration in the database, every child will be assigned a vision rehabilitation therapist, who may help with guidance and counselling in the home, daycare or school. Optical rehabilitation such as spectacles, contact lenses, magnifying glasses and binoculars will be economically supported.

In Denmark, the provision of diagnostic and highly specialised treatment lies within the tertiary healthcare sector, primarily hospitals; whereas the responsibility for other healthcare services, including rehabilitation, lies in the primary healthcare sector—the municipalities.<sup>6</sup> Therefore, patients and parents must navigate between different healthcare sectors in their patient trajectory to get the help they need, which may create unnecessary burdens and delays. This may be of particular concern around the time of diagnosis, which is given at the hospital and the following formal support and help provided by the municipalities, because of a possible delay due to the shift in sectors.

This qualitative study sets out to describe the support needs of parents caring for an infant with visual impairment or blindness around the time of diagnosis, with the purpose of elucidating potential uncovered need for support and help.

## MATERIALS AND METHODS

We used a descriptive qualitative method based on the theory of critical psychology to explore the experiences and needs of families to an infant with newly diagnosed severe visual impairment or blindness. Critical psychology draws on an explicit focus on the subject's (eg, the family's) lived experiences but within the social context of their origin.<sup>7 8</sup> Critical psychology originates from a historical dialectical materialism where subject and context cannot be seen as separated but are constantly intertwined and mutually dependent. This is to be understood as a constant double relationship where the subject creates its own living conditions but at the same time is also subordinated to living conditions that originate from the social context.<sup>7 8</sup>

The parents were recruited from the Department of Ophthalmology at Rigshospitalet, Denmark in relation to appointments in the clinic or by phone or email. The main criteria for participation were as follows: (1) to be a parent of a visually impaired or blind child diagnosed in infancy (0–1 year of age), (2) learning of the diagnosis within the past 5–6 months and (3) the child should be in the Registry for the Blind and Partially Sighted Children.

This timespan was partly chosen because most are diagnosed in the early years, and partly due to the authors' experience of this timespan being particularly vulnerable.

We excluded families of children with severe systemic comorbidities that could interfere with the child's development at the time of the interview to keep a strong focus on the impact of visual impairment or blindness.

Parents were informed on the study and given an information leaflet. If they agreed to participate, contact information was exchanged, and a meeting was arranged. All invited parents agreed to participate, and there were no dropouts during the study. Parents were interviewed one time only.

The study was performed using a semistructured interview guide (online supplemental file 1). The interview

guide was intensively discussed and revised in collaboration between all authors of the study. The interview guide included the following five themes: (1) the initial concern about a potential visual disorder in the infant; (2) establishing contact with the hospital, focused on the process of investigating the reason for concern leading to receiving the diagnosis; (3) establishing contact with the vision rehabilitation therapist in the municipality; (4) the experience of everyday life and expectations of the future; (5) closing of the interview—room for final comments.

The themes followed a chronological order. The methodological and theoretical approach also materialised in the development of the semistructured interview guide where we were interested in the family but also had a focus on the surrounding environment, network, siblings, etc.

The same two researchers were present at all interviews. Interviews could be performed in the homes of the families or at the hospital according to parents' preferences. Interviews were audio-recorded and transcribed at a later time point. Interviewer 1 (NM) was responsible for conducting and transcribing the interviews. Interviewer 2 (AR) ensured that all aspects of the interview guide were covered by the interviewer and that potential uncertainties or vague/misleading answers were resolved during the interview.

The analytical methodology used for the interview data was a thematic analysis, which embraces the dynamic process of moving back and forth throughout the different phases of the analysis.<sup>9</sup> The thematic analysis allowed us to sort data attained from the interviews in manageable units.<sup>9</sup> Data were organised by two of the authors using a category scheme. The category scheme was arranged in compliance with our interview guide. Having read and reread the scheme and all the data in its entirety, we identified patterns, themes and relationships within our data.

The data sample was characterised by in-depth material, since data collection continued until redundancy and saturation were achieved.<sup>9</sup> Informants were assigned a code to provide anonymity and confidentiality. When referred to in the text, informants are identified by a code—I:1 (informant number), mother or father, 1 (age of their child at interview).

Before the beginning of each interview, the informants received written and oral information about the study and that study participation was voluntary and that consent could be withdrawn at any time point. Informants signed an informed consent form (online supplemental file 2).

## Patient and public involvement

None.

## RESULTS

We interviewed eight parents (five families) of children under the age of 2 years diagnosed with a visual impairment or blindness before the age of 1 year. All five children were blind or severely visually impaired from birth.

**Table 1** Overview of interviews

Interview	Parents present at the interview	Number of children in family	Family structure
Interview no 1	Mother and father	2	Cohabiting
Interview no 2	Father	2	Cohabiting
Interview no 3	Mother and father	3	Cohabiting
Interview no 4	Mother	1	Single parent
Interview no 5	Mother and father	3	Cohabiting

All children had congenital eye conditions characterised by panocular malformations but were otherwise healthy. Four out of five interviews were conducted in the homes of the families, one was conducted in the hospital in connection with the family coming in for a routine examination. The interviews were completed between May 2021 and January 2022 (this period lasted longer than expected due to the COVID-19 pandemic). The interviews lasted approximately 1–1.5 hours, resulting in approximately a total of 80 pages of transcribed text. An overview of the interviews is presented in [table 1](#).

### Overview of interviews

At the time of interview, four out of five children were under the age of 1 year. These children were taken care of at home by a parent on parental leave. One child, age 1.5 years, attended daycare with normal-sighted peers. For the families with more than one child, the child with the impairment was the youngest sibling.

The thematic analysis identified three themes.

### Recognition and reactions during the time of diagnosis

The concern about a potential visual impairment presented itself in different ways for the parents and with various timespans with a median of 1–2 weeks after birth. In some cases, the parents were the first to notice something different about the eye or the periorcular area. In other cases, it was a community nurse who raised concern, for example, due to a lack of eye contact, involuntary eye movements, or abnormal physical appearance of the eyes or periorcular area.

Whether it was the parent or the community nurse who first articulated concern, this immediately entailed a both shocking and overwhelming experience: “We had an appointment right away, and my world totally collapsed. I am a single mother, but I have tried, it has been a very long process” (I:6, mother, <1).

Moreover, learning the infant had a visual impairment brought out reminiscence of losing the possibility of maintaining a worthy life. As a mother of a blind infant explained: “Well I just think that we were pretty sure of that our life would end (...). That is, we are going to have a child who can’t do anything at all, because of his blindness. Well, none of us have any experience with blind people at all, and to us, it was just like saying, nothing matters anymore, and then just let him be” (I:1, mother, <1).

This quote sums up a thought raised by all the parents on how the impairment would impact the life of their child, and which possibilities they would have for maintaining a worthy life, for example, would the child be able to obtain education and be independent as an adolescent or adult. All parents expressed concerns about how the impairment would impact the family, for example, the possibility for parents to maintain their job, having to move, etc, elevating potential stressors: “Will one of us never return to our job, can we afford to stay in our house, are we going to rethink moving one more time (...). When so many things happen at one time, things we don’t have to worry about right now, then I just think things stumbles a little bit” (I:2, father, <1).

Likewise, one mother expressed concern on how to manage the upbringing of the child; hence, children also learn by engaging with peers and observing how others behave: “(...) That you must explain your child, that it’s okay to take ones coat off when it’s warm outside, but it’s not okay to take one’s trousers off. You don’t have to explain such things to a child that can see, because they have already observed that no other people walk around without trousers. Well, I just think that the ‘social’ aspect of upbringing a visually impaired child is a big responsibility” (I:1, mother, <1).

Additionally, the diagnosis initiated a process where the families had to accept the loss of a healthy child, and to rethink and reorganise their expectations of the family to be by seeing their family in a new, unknown and different light: “So, one might say, that he has overcome a lot of things, and I hope that things are moving in the right direction. I’m doing what I can to help him in the best possible direction” (I:6, mother, <1).

Common for all the parents was that once the possibility of an impairment was raised, everything happened quickly which on one hand made the situation even more overwhelming and extreme, but on the other hand also made the parents feel safe, as expressed in the following quote: “You can say that the process is extremely overwhelming, and because everything happens so quickly, just makes it even more devastating. But it was also a good thing that things moved quickly. (...) One can’t just sit and wait around when you have been told that you child is blind or have cancer, then you just have to get going, right” (I:1+2, mother and father, <1).

Six out of eight parents described being given the diagnosis also emphasised a general concern of what might else be wrong with their child, leaving them in heightened preparedness for handling a sudden emergency: “I saw that my baby is not fine, so that is like hard, and it is very difficult to accept that. And still, it’s fear all the time, will he have other problems” (I:4, mother, <1). For all parents, this concern had an interconnectedness with the concrete diagnosis of their child which had embedded a risk of associated comorbidities that could present at a later stage: “Then you also realize that glaucoma also is a concept that you have to relate to, and obviously that is something that we are really afraid of her [daughter] getting” (I:3, father, 1).

When asked what support and help would have been most helpful at the time of diagnosis, parents indicated that they wanted reassurance of everything ending well: “If I were to say it face-to-face, then I would say, that even though things right now seem completely hopeless, then everything is going to work out. Well, it will get better, and try to stay calm. It’s some really skilled people that are working with your child right now, and they know what they are doing, and they are doing everything possible to help” (I:3, father, 1).

### Family, network and struggles

Support from family and friends was perceived as crucial for relief and relaxation in everyday life. Support from family and friends was provided in many ways, ranging from conversations to practical assistance, for example, babysitting older siblings in relation to visits to the hospital. “But we have a close relationship to both sets of grandparents, so I just think that he [big brother], the days where we had to go to the hospital, he was at his grandparents, and that was something he thought of as quite awesome” (I:1, mother, <1). Not all parents had close relatives living nearby and they reported a lack of support and help from relatives, also leaving them with having to manage on their own, and not having anyone to share their burdens and griefs with: “He was crying all the time, like first 3–4 months, like no, he would not allow me to take a little break. He was not sleeping, and dad working at days, and girls also disturb so much, and nobody in this country, like you know, when you are tired you can see all the windows look like everybody is happy, but you are not” (I:4, mother, <1).

Likewise, four parents also reported that even though they had someone to share their burdens with, they also felt responsible for not hurting the other person with their grief as in to protect the ones nearest even though the parents were hurting themselves. “Well I have had some friends, that I have talked to, and then off course my mother who are so connected to us, but it can also be very hard at times when it’s one that you are very close to, because she has also been very sad and sad on my behalf. (...) But the thing with all the time protecting one another, and with my mother in this situation, where I haven’t turned so much to her” (I:6, mother, <1). The

same form of protection of ones nearest in times of grief is also experienced between spouses: “Like my father was dead, my mother was dead (...), and I’m alone. I don’t have any brother or friend closely where I share. I can’t share with my wife, I know she is the mother, she has more, if I share something, then we fall down” (I:5, father, <1).

To be able to share and process the hard feelings associated with having an infant with a visual impairment or blindness, six out of eight parents expressed a general need for professional emotional support, for instance, sessions with a psychologist. However, only one out of eight had seen a psychologist. Reasons for not seeing a psychologist included long waiting lists, difficulties getting a referral and that it was not free of charge. Most parents had considered the possibility of connecting with other parents in the same situation but had not established any contact. Only three parents had engaged (virtually) with parents of children with the same diagnosis: “I have found a network of people who have children with the same diagnosis or have the diagnosis themselves in USA. Talking with someone who has older children, of what to expect of the future, that was what I needed the most” (I:7, mother, <1).

All the parents reported having experienced struggles after becoming parents to an infant with an impairment. The parents defined struggles as having to secure the right support and help for their child and family: “I just think, that when you have a child that is a little bit different than the rest, then you will experience some struggles. And that just requires an enormous amount of effort, a lot I would say. And maybe especially concerning the blindness, because no one really knows what to do” (I:1, mother, <1). One couple experienced having their claim for compensation for loss of earnings rejected, which made them file a complaint to their municipality. In the meanwhile, a local newspaper interviewed them about their point of view of the situation resulting in a sudden change of event: “After 2–3 days we were called in for a new meeting (...) and are told that we now are granted compensation for loss of earnings” (I:3, father, 1). Not all parents experience receiving/being granted those services that they apply for, as a father explained: “I have requested the municipality almost 20 times, but they refuse me clearly, and school refuse me clearly; we don’t give you, we don’t give you anything” (I:5, father, <1).

### Interaction with healthcare professionals

After being given the diagnosis, the parents experienced having to attend to a considerable number of appointments both in the hospital at different departments such as the ophthalmological, genetic, etc. Moreover, they also had appointments in their own home with a vision rehabilitation therapist, community nurse, physiotherapist, etc. The parents estimated that they would have two to three visits every week at hospital or home in the first 5–6 months after diagnosis. Appointments were experienced both as reassuring and calming but also as a stressor in everyday life as they had to coordinate visits at different

places and time points: “I just had to say ‘Hey try and listen to this, we have been at the hospital several times a week’, I’m not able to cope with more or having to adjust to more things. It’s not because you don’t want to, but you just have a lot on your hands, both having to handle the emotional challenge of having a child with an impairment, but also handling all the practical aspects of everyday life” (I:6, mother, <1).

In relation to these appointments, the parents also describe a feeling of being responsible for coordinating the course and bringing messages from one specialist to another specialist. “I have always been very observant on whom I’m asking what question, because they [specialists] do not talk to each other” (I:1, mother, <1).

Six parents described the initial meeting with healthcare professionals as a securing process, and an act towards gaining knowledge about their reason for concern. Despite this otherwise positive experience, all parents also linked meetings with some healthcare professionals to feelings of uncertainty of the trustworthiness and quality of the healthcare professionals’ competencies: “Because I don’t know what my vision rehabilitation therapist doesn’t know, so everything I know, is something that I have from her” (I:1, mother, <1). This uncertainty led some parents to turn away from some healthcare professionals and as an example chose to attend highly specialised training elsewhere: “We have deselected their therapists” (I:3, father, 1).

All parents described situations where they had felt that the healthcare professional had helped them in an extraordinary way, meaning more than one could anticipate or expect. These situations are some that the parents emphasised as special and extra helpful. As a mother explained: “You can always call her [the doctor], and she has been super flexible (...). It meant the world, that you had someone who was super flexible, it’s a massive, massive advantage” (I:6, mother, <1). And as another mother described: “It was so kind of her to stay late for work that Monday. We drove directly from Skejby to her [in Glostrup] and sat and talked with her for 1.5-hour Monday evening (...). I just think that it was very exemplary what she [doctor] did, she invited us that Monday, and she was very open (I:1, mother, <1). Another family had a similar story to tell: “Yes, she [doctor] is the hope. Like I think in this whole case, like if I feel an angel, like she listened to us very carefully, and she looked at him [child] very carefully. And then she gave us a hope, like we will try, maybe he will get a light and a difference between day and night” (I:5, father, <1).

On the other hand, seven parents also described opposite experiences: “What a mother can do, because I have one son in the whole world, but they have a lot of patients, so they don’t treat my son as their son, they just treated him as a patient” (I:4, mother, <1). Situations where parents feel as merely a patient is defined by the act of the healthcare professionals. When healthcare professionals happen to say the wrong name of the child and do not make an extra effort to bypass rigid systems for the

best of the family, this is interpreted poorly. “Then they [healthcare professionals] will read the file, and that’s fine, but then you know right at first in the file, one has written the wrong name, then they keep calling him by the wrong name. You know, that’s just some things where you ...” (I:1, mother, <1).

## DISCUSSION

We performed a qualitative study of the experiences and support needs of parents caring for an infant with visual impairment or blindness around the time of diagnosis.

We found that it was an overwhelming experience for the parents to learn that their infant was blind or severely visually impaired and that this immediately led to concerns for the child’s possibility to obtain a worthy life in combination with a worry for additional comorbidities. Parents were concerned that the impairment would affect the lives of other family members. Consistent with prior studies, we found that learning the diagnosis initiated a response similar to the reactions of a traumatic crisis, for example, feeling of losing control, loss of a worthy life for the child and loss of the family to be.<sup>5 10 11</sup> This reaction is quite identical throughout the parents’ descriptions of their experiences and stories, despite the variation in the diagnosis given.

The parents themselves apply different strategies on how to manage, accept and cope upon learning the diagnosis. Parents refer to their own effort in improving the situation for their child, that they feel there are competent people around them and how they accommodate the special needs of their child into the daily life of the family. However, despite the parents’ own efforts, parents themselves expressed a need for some form of reassurance that everything would end up fine. Nygård and Clancy<sup>12</sup> found that if a sense of hope in an otherwise hopeless situation could be established, parents of children with special healthcare needs could mobilise a feeling of being able to overcome adversity. To define hope as a concept lies beyond the reach of this study but inspired by the work of Duggleby and colleagues<sup>13</sup>, hope can be considered as a profound feeling and faith of something better to come within a framework of uncertainty. Ophthalmologists, optometrists, nurses and vision rehabilitation therapists are well positioned to outline the concrete meaning and expected influence of the diagnosis, and thereby give rise to hope of a worthy life for both the child and their family. McDowell’s study on parents of children with cerebral visual impairment also shows how healthcare professionals have a unique position to empower parents around the time of diagnosis by providing them with clear and relevant information.<sup>14</sup> An exploration of the parents’ experience of the time of diagnosis offers healthcare professionals insights into factors that could potentially support and help mobilise the parents’ own competencies in managing their new situation, allowing them to preserve resources to reorientate in their new life situation. This knowledge calls for healthcare professionals to

be proactive in their interactions with these families by actively outlining individual needs for mobilising hope and thereby reducing the feeling of hopelessness.

We identified various supportive functions as important at the time of diagnosis. First and foremost, the support and help from the parent's close network stood out as highly important and it made a positive influence on how parents considered their situation. On one hand, we saw how a perceived good and competent network enhanced the feeling of being secure. On the other hand, we could detect a vulnerability in families who only had sparse or no network to mobilise in times of trouble. This enhanced the strain on the parents. This finding emphasises the importance of directing focus to families who could be considered as vulnerable or deprived of a social network and be attentive of their potential increased need for support and help.

Irrespective of the strength of the network, most parents expressed that talking to a psychologist could have been a relief and support around the time of diagnosis. However, only one out of eight parents had talked to a psychologist. The reason for this seemingly small number is unknown but could give rise to an exploration of potential obstacles in the referral practice to the formal support in the form of a psychologist.

Parents wanted to connect with other parents who have a child with the same diagnosis. For the parents in this study, the diagnosis was the thing they felt they could share, not the visual impairment or blindness, but the concrete diagnosis and its specific expression and implications on their child and everyday life. Concerning parents of children with rare diseases, Baumbusch and colleagues<sup>15</sup> found that they could regard other parents as peers irrespective of the cause of the rare disease, despite differences in diagnosis and prognosis. The National Association of Parents of Blind and Visually Impaired is a Danish network for parents of children with blindness or visual impairment. Despite the origin of this network, none of the parents were members, and most of the parents did not know it existed. It was a surprising finding that parents sought relations to others affected by the same diagnosis rather than others affected by the same degree of visual impairment.

We found that families had to spend time and emotional resources to obtain perceived rights for support and help, for instance, compensation for loss of earnings. Similar findings within a broad range of disabilities have been identified in other studies.<sup>16 17</sup> Our parents reported inconsistencies in granting support, potentially suggesting that deprived families are at a higher risk of not receiving justified support and help. However, this should be studied further to illuminate potential inequalities.

The number of appointments at hospitals and home was demanding for many families and put a strain on the family. Caring for a sick child is associated with extra activities beyond those involved in caring for a healthy child—extra activities that can represent a potential source of stress and burden.<sup>1 2 12 18 19</sup> Additionally, we found that

parents felt they held a large share of the responsibility for coordinating appointments and bringing messages from one sector to another. Relieving the burden and stress linked to both attending appointments and upholding a coherent patient trajectory from the parents' shoulders may give them more time and energy to concentrate on becoming a family. The coordination between appointments must be explored to identify factors influencing negatively on workflows and direct critical attention and reflection to the number of appointments. Moreover, it seems that parents may benefit from a written overview of what they can expect, which healthcare professionals and healthcare sectors will be involved in the process and what they can expect from each and where they can get help.

Finally, we found that the interaction with healthcare professionals is a complicated act. Parents assess the quality of the interaction with healthcare professionals and evaluate their competencies.<sup>12 20</sup> Meeting competent healthcare professionals gives rise to hope and helps the parents cope with the uncertainty. However, a devaluation of competencies makes parents withdraw from the interaction, and if possible, seek out alternatives. The assessment of the quality of the interaction is closely connected to the feeling of being viewed as a family or being left with the feeling of their child is regarded as 'just a patient'. Parents want their child to be seen and treated as more than 'just patients'.

Healthcare professionals hold the responsibility for creating a constructive and professional collaboration with the families with consideration for their individual concerns and needs. Information and individual communication are factors that help reduce anxiety and enable a good starting point for constructive collaboration.<sup>15 21</sup>

Our study was based on qualitative interviews with parents of children diagnosed with visual impairment or blindness before the age of 1 year. Our study provided rich data material, but the study also has some limitations. Due to our study sample of eight parents, the results are not generalisable to all parents of children with visual impairment or blindness around the time of diagnosis. We sought to minimise recall bias, by interviewing parents within 6 months of the diagnosis but it remains a risk, as parents relied on their retrospective experiences.

## CONCLUSION

Based on the interviews with parents of infants with newly diagnosed visual impairment or blindness, it seems the foremost lesson for healthcare professionals is to bring hope at a time when all hope may seem to be lost. Second, attention should be focused on families with no or sparse supportive networks as they are more likely to experience heightened stress and burdens. A call for emotional support in the form of a psychologist as well as peer networks must be investigated. Third, coordinating appointments between hospital departments and at-home therapies as well as reducing the number

of appointments to allow parents time to establish a family relation with their child is also important. Parents respond well to competent healthcare professionals who keep them informed and who see their child as an individual rather than as a diagnosis.

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