LIVING WITH RETINOBLASTOMA: PSYCHOLOGICAL ISSUES

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Introduction

In 2000 the Trustees agreed to a joint funding proposal examining psychological aspects of the treatment for retinoblastoma including issues relating to service delivery. Together with the Open University, we funded a project directed by Dr Sarah Norgate and Dr Karen Littleton from the Centre for Childhood Development and Learning at The Open University.

The project involved a series of studies investigating the impact of Rb on 34 families living in the UK, with a child aged under 6 years, diagnosed with either unilateral or bilateral form of the disease. Of these, 24 participated in the ‘comprehensive’ study, involving home visits and 10 families were involved by questionnaire. A summary of the main findings from the project appear in the 10 sections below.

1. What sort of wording might be used in future campaigns to raise public awareness of the first signs of Retinoblastoma?

In order to minimise time to diagnosis, it is critical to find out which *factors* led parents to either postpone or seek medical advice about their child’s eyes. Identifying any factors common across a number of parents, has the potential to inform the design of future public awareness campaigns so that information is presented in the most relevant ways to new parents, parents-to-be, as well as to health professionals.

Our study involved obtaining information from parents about their first reported symptoms of Retinoblastoma (e.g. some parents report a “flash” or being able to “see right through the eye” – often referred to as leucoria) as well as the various factors which influenced their decision to seek or not seek medical advice. We found that by far the most common reason why parents reported postponing seeking immediate medical attention was the attribution of their concerns to various lighting conditions rather than the child's eye. Parents also reported that they postponed seeking medical attention as they believed the early sightings to be a 'one-off'. These outcomes suggests that the content of future public awareness raising campaigns about Retinoblastoma should focus on this sort of contextual information as well as the nature of presentation of the first signs. For example, it would be important to emphasize that regardless of the lighting conditions – and regardless of whether or not this forms the only sighting - it might not *feel* sufficient but actually is sufficient to seek medical advice.

Another outcome from this study was the production of an archive of parental descriptions of the initial symptom, which has the potential to act as a resource for informing the development of any future awareness-raising campaigns including those specifically targeted at health professionals.

2. What are parental needs at different time-points in the treatment process?

What are parental priorities in terms of the information and support needs required at different time-points immediately preceding diagnosis and across treatment? This question is highly relevant in the case of Retinoblastoma where, compared to other conditions of childhood, there is a particularly tight time frame between referral, diagnosis and medical treatment which includes the possibility of the surgical removal of an eye.

Parental views of the *importance* of different aspects of information or support and the extent to which *needs* for information or support were met were investigated by a 'parental needs assessment at three time-points – preceding diagnosis, before enucleation and in learning to live with a prosthesis. A summary of findings obtained in this UK health context in the period 2003-4 appear in Tables 1-3. As these tables prioritise the information and support needs of parents in the time-points before diagnosis, before enucleation and at the time a child is living with an artificial eye, they have direct implications for the planning of future service resources.

Table 1 ***Before diagnosis*:** (N = 34)

		Importance rating	Need Met?
1.	Knowing that enucleation might be a necessary procedure	Utmost	Reasonably well
2.	Knowing what Rb is	Utmost	Somewhat
3.	Knowing what would happen to my child during examination, and how it would feel	Utmost	Almost adequate
4.	Having written information about what to expect on the 1st hospital appointment	Utmost	Barely adequate
5.	Knowing how to work with your consultants to get what you want/need	Utmost	Barely adequate
6.	Knowing about the risk of secondary cancers	High	Barely adequate
7.	Knowing what causes Rb	High	Barely adequate
8.	Having written information about Rb	High	Barely adequate
9.	Knowing 'track records' with respect to the treatment of Rb	High	Barely adequate
10.	Having information on the quality of care at the hospital	High	Almost adequate
11.	Knowing how to get answers without feeling like you are bothering people	High	Almost adequate
12.	Knowing what to say to my child after the first hospital appointment	High	Reasonably well
13.	Knowing what to say to my child about the 1st hospital appointment	High	Almost adequate
14.	Having 'phone call about what to expect on the 1st hospital appointment	High	Barely adequate
15.	Knowing where to get the latest information on treatments	High	Barely adequate
16.	Knowing what technical medical terms mean	High	Not really
17.	Knowing how to assess the quality and accuracy of the information you are getting	High	Barely adequate
18.	Having a written list of questions to ask before talking to consultants	High	Barely adequate
19.	Knowing about others' personal experiences of living with Rb	Substantial	Barely adequate
20.	Knowing that my child would be offered preparation through play	Substantial	Somewhat met
21.	Knowing how to finance visits to hospital	Considerable	Barely adequate
22.	Knowing about others' personal experiences before they attended their 1st hospital visit	Considerable	Not met

Table 2 ***Needs after diagnosis and before enucleation:*** (N		Importance rating	Need Met?
23.	Knowing what would happen to my Child before, during the operation, and how it would feel	Utmost	Reasonably well
24.	Knowing what Rb is	Utmost	Virtually Totally met
25.	Having written information about Retinoblastoma	Utmost	Well met
26.	Knowing what causes Rb	Utmost	Reasonably well
27.	Knowing where to get information about living with an artificial eye	Utmost	Almost adequate
28.	Knowing about the risk of secondary cancers	Utmost	Somewhat met
29.	Having written information about hat to expect on the day of the operation	Utmost	Somewhat met
30.	Knowing how to work with your consultants to get what you want	Utmost	Somewhat met
31.	Knowing how to deal with my child's questions	Utmost	Somewhat met
32.	Knowing what to say to my child after the operation	High	Somewhat met
33.	Knowing what to technical medical terms mean	High	Somewhat met
34.	Knowing how to deal with other people's reactions to my child after enucleation	High	Almost adequate
35.	Knowing how to get answers without feeling like you are bothering people	High	Reasonably well
36.	Knowing that my child would be offered preparation for play before the operation	High	Reasonably well
37.	Knowing what to say to my child about the operation	High	Reasonably well
38.	Having information about the quality of care at the hospital	High	Almost adequate
39.	Knowing how to assess the quality and accuracy of the information you are getting	High	Almost adequate

Table 2 (continued)

40	Knowing 'track records' with respect to the treatment of Rb	High	Almost adequate
41	Having access to 'My Pretend Eye' or any similar story	High	Well met
42	Having contact with another family with a child who is an artificial eye wearer	High	Almost adequate
43	Having to access to Dino or any similar artificial eyes	High	Almost adequate
44	Knowing about others' personal experiences of living with artificial eyes	High	Barely adequate
45	Knowing about others' personal experiences of living with Rb	Substantial	Almost adequate
46	Having a written list of questions to Ask before talking to consultants	Substantial	Almost adequate
47	Knowing about others' personal experiences	Substantial	Somewhat met
48	Knowing how many other people have Rb	Substantial	Reasonably well met
49	Having a 'phone call about what to expect on the day of the operation	Substantial	Almost adequate
50	Knowing how to finance visits to hospitals	Substantial	Somewhat met
51	Knowing how many other children live with an artificial eye	Substantial	Barely adequate
52	Having contact with an adult artificial eye wearer	Considerable	Not met

Table 3 Needs when living with an artificial eye (N = 32).

		Importance Rating	**Need Met?**
53.	Knowing how to work with your orbital prosthesist to get what you want for your child	Utmost	Well
54.	Having specific written information about care and cleaning of artificial eyes that you can take home	Utmost	Reasonably well
55.	Knowing what would happen to your child during each visit to the artificial eye clinic	High	Reasonably well
56.	Having information on the quality of care within the artificial eye clinic	High	Somewhat
57.	Knowing others' personal experiences of living with an artificial eyes	High	Almost adequate
58.	Knowing how to get answers to questions without feeling like you are bothering people	Substantial	Reasonably well
59.	Knowing how many other children live with an artificial eye	Considerable	Almost adequate

3. What are parental preferences for access to information and support, in retrospect?

What are parental views about the optimal ways to access information and support? Whilst recognizing that no single formula can possibly suit everybody, as Tables 4 – 7 show, the study found some striking trends regarding parental preferences, which have direct implications for informing the planning of future resources in service.

Table 4 Preferred ways of accessing information and support before diagnosis, in retrospect

	Total responses	
A: Receiving written information	30	(21.4%)
B: A phone call from the Childhood Eye Cancer Trust	26	(18.6%)
C: Phone call to the hospital	4	(2.9%)
D: A phone call to the Childhood Eye Cancer Trust	9	(6.5%)
E: Look up on WWW	14	(10%)
F: Join electronic group	6	(4.28%)
G: Talking with family with child with Rb	19	(13.6%)
H: Talking with adult with Rb	9	(6.5%)
I: Wait until appointment	14	(10%)
J: No preference	2	(1.4%)
K: Other*	6	(4.2%)
Missing data	1	(0.7%)
Total (34)	**140**	**100%**

* = includes video

Table 5 Preferred ways of accessing information and support before enucleation, in retrospect

	Total	%
A: Receiving written information	27	(18.8%)
B: A phone call from the Childhood Eye Cancer Trust	25	(17.4%)
C: Phone call to the hospital	11	(7.6%)
D: A phone call to the Childhood Eye Cancer Trust	10	(6.9%)
E: Look up on WWW	14	(9.7%)
F: Join electronic group	6	(4.2%)
G: Talking with family with child with Rb	23	(16.0%)
H: Talking with adult with Rb	10	(6.9%)
I: Wait until appointment	10	(6.9%)
J: No preference	2	(1.4%)
K: Other*	4	(2.8%)
Missing data	2	(1.4%)
Total (34)	**144**	**100%**

* = “video”

Table 6 Preferred ways of accessing information and support in relation to the first visit to an artificial eye clinic (AEC), in retrospect

	Total	**%**
A: Receive AEC leaflet	24	(19.5%)
B: Receive a phone call from the AEC	23	(18.7%)
C: Receive a phone call from someone in Childhood Eye Cancer Trust	17	(13.8%)
D: Make a phone call to the AEC	5	(4.1%)
E: Make a phone call to the Childhood Eye Cancer Trust	1	(0.8%)
F: Look up info on WWW	10	(8.1%)
G: Direct questions to electronic support group	1	(0.8%)
H: Read emails about artificial eyes on electronic support group	5	(4.1%)
I: Talk with family with child with artificial eye	20	(16.3%)
J: Talk with an adult/young person artificial eye user	8	(6.5%)
K: I am user and have access to info	0	(0%)
L: No info required	0	(0%)
M: No preference	2	(1.6%)
N: Prefer to wait until appointment at AEC	2	(1.6%)
O: Other	1	(0.8%)
Missing data	4	(3.3%)
Total (N=34)	**123**	**100%**

Before the time of the first appointment for the fitting of a prosthesis, there is usually the freedom of a larger time window and therefore more flexibility for the timing of information than at earlier stages of the treatment process. Table 7 shows that the most preferred time-point for access to resources, depended on the medium of the contact. Overall, written information about the service was mostly preferred a week after enucleation whereas a ‘phone call from the service would have been preferred about 2 weeks after enucleation.

Table 7 Preferred time to access resources about 1st visit to artificial eye clinic

Time-point	Phone call from AEC	Leaflet from AEC	Contact with family with child artificial eye user	Contact with adult artificial eye user
A: At time before enucleation	3 (8.8%)	5 (14.7%)	6 (17.7%)	3 (8.8%)
B: About week after enucleation	6 (17.7%)	13 (38.2%)	2 (5.9%)	1 (2.9%)
C: About 2 weeks after enucleation	11 (32.4%)	6 (17.7%)	5 (14.8%)	2 (5.8%)
D: About 2 weeks before first visit to clinic	0 (0%)	0 (0%)	1 (2.9%)	2 (5.8%)
E: About 3 weeks before first visit to clinic	1 (2.9%)	1 (2.9%)	1 (2.9%)	0 (0%)
F: About 4 weeks before first visit to clinic	0 (0%)	0 (0%)	1 (2.9%)	0 (0%)
G: About a week before first visit to clinic	8 (23.5%)	6 (17.7%)	3 (8.8%)	0 (0%)
H: A day or two before first visit to clinic	2 (5.9%)	0 (0%)	5 (14.8%)	5 (14.7%)
I: No time preference	0 (0%)	0 (0%)	3 (8.8%)	5 (14.7%)
J: None of this type of contact needed	0 (0%)	0 (0%)	3 (8.8%)	10 (29.6%)
K: Other time:	0 (0%)	0 (0%)	0 (0%)	0 (0%)
L: Missing data	3 (8.8%)	3 (8.8%)	5 (11.7%)	6 (17.7%)
Total	**34**	**34**	**34**	**34**

4. What were typical parental reactions across different time-points in the treatment process?

Given the low incidence of Retinoblastoma, and the lack of easy access to others in the same situation, some parents of newly diagnosed children may want to find out about how other parents reactions after their child's diagnosis. The parents in our study reported that upon diagnosis they feared for their child's life and were naturally anxious that 'it could have/should have been picked up sooner':

> *'We were very fearful for his life.'*
>
> *'We were going into the unknown and we just didn't know what was happening.'*
>
> *'I was just worried that we hadn't caught it in time…annoyed with myself that I hadn't sort of pushed for a hospital appointment sooner.'*
>
> *'I was just angry really, angry at the people that I thought could have done something sooner and he could have been referred sooner and then maybe this wouldn't have been as bad as it was, just very angry.'*
>
> *'I felt angry that we had been, all the literature that you ever read about squints is very reassuring..they never tell you…that I've never anywhere read that the squint could be an indicator of Retinoblastoma, and that really did make me angry because if I had known when I first saw that he had a squint and there was any possibility it could be anything other than a relatively trivial thing I would have, you know, hammered on doors.'*

Immediately prior to enucleation, parents talked about dealing with other people's emotions and the challenge of finding ways to tell people, particularly other family members. The question 'Why?' was also paramount in their minds:

> *'…having to deal with other people's emotions like grandparents and friends, who obviously were naturally very concerned and upset, but I found that quite difficult dealing with their emotions and as well as trying to keep my own under control.'*
>
> *'What's harder, another thing which is hard is telling other people because you almost have to go through it for them every time you phone them and tell them. Its pretty hard being a bearer of very bad news, and sometimes you feel strong enough and you do a group of people, and then you feel I just don't want to do this. I don't want to phone*

> *someone up and ruin their evening, but equally you feel that people need to know. So that is difficult as well.'*

> *'Why us? Why him? Not us, why him? Is there any reason? I mean why? Especially when there's no evidence of it on either side of our families. Why him?'*

> *'I just think 'why us' really . . . you know. Why X? Why on earth has this happened to us, and it's an incredibly rare disease, that nobody has ever heard of, and what on earth has X done to deserve this. Lots of things really, I suppose selfish things really, you think… can't believe that… this sort of thing only happens to other people, not to you. All the sort of cliché stuff really but I guess it was what we were feeling.'*

In the month following enucleation, parents had the concerns of after-care and anticipating and dealing with others' reactions to their child's changed appearance:

> *'Immediately afterwards it was just sort of looking after his eye, and making sure it didn't get infected, wondering if the swelling and the bruising, and the way it was healing was the right way, cos obviously once I was back at home that was it, I didn't get any aftercare support, I just had to deal with… all that on my own. So looking after his eye, just cleaning it and not knowing really whether what was happening was normal or not was quite difficult.'*

> *'…people, not making fun of him, but obviously he looked different. I remember going out in the park, and 'look at him'. It really upset me, and he had to have a shell in for two months, so I obviously took him out. Obviously he looked different, that upset me because he did look different'*

> *'fears about how other people would react to it when she went out before she had the eye fitted, and I found that it was the adults more than the children who stood and stared at her.'*

Beyond this time-point, parents expressed concern that the cancer would return and/or that 'the other eye will be lost'. Moreover, there were worries in relation to handling of the artificial eye and the reactions of others with specific reference to teasing and bullying:

> *'Well the biggest fear is the eye ……or to get some other form of cancer…'*

> *'I think my biggest fear is that he's not going to have an accident where is going to, something's going to happen to his right eye…that's my biggest fear that he'll obviously be blind…Cos he's only got one eye, so obviously be worried that he's not going to meet with some sort of accident at nursery, or at you know and eventually at school…'*

> *'Basically taking care of his artificial eye is probably the one frustration at the moment. It's a case of . . .you know . . . he doesn't like having it taken out and cleaned. I'm trying to encourage him to actually be more proactive in that touching, and trying to put it in.*

> *'There are the health ones, and also in your back of the mind you're thinking well what's it gonna be like if she grows up, is she going to find bullying issues and other sort of stigmatised in any way because of it, either by other people, institutions like insurance companies, and stuff like that.'*

> *'Bullying at school as he gets older. He's only in his reception year at school, but I think obviously because he's a bit different in terms of other kids perception that there may be an issue later on for him. At the moment he's sort of . . . absolutely wonderful about things, but that would be my main fear.'*

5. What helped parents cope in the month following enucleation?

One of the distinctive features of treatment for Retinoblastoma is the rapid onset of treatment following diagnosis. Our study was specifically designed to identify those coping strategies considered to be helpful in the month following enucleation. This was selected as an important time-frame to consider in an initial study of coping, as at this point parents have had relatively little time to adjust to the diagnosis of Retinoblastoma and the associated treatment.

Our analyses revealed that at this time-point, the importance of maintaining family integration, cooperation and keeping an optimistic definition of the difficult situation were emphasized as being important. Parents also stressed how helpful they found communication with other parents and in keeping in consultation with medical staff.

6. What were typical child reactions following enucleation?

The project did not identify parental reports of any severe or substantive behavioural changes that emerged as being typical of the group of children with Retinoblastoma as a whole. Parents cited 'sleep patterns' as the most changed behaviour (although overall this was only rated as showing mild change). However, that preparation for anaesthesia emerged as the most distressing aspect of the treatment process, coupled with parental reports of sustained/increased anxiety over successive EUAs, indicates that urgent research is needed in this area.

7. Views and experiences of siblings

As the diagnosis and treatment of childhood cancer obviously places considerable demands on family life, there is a risk that siblings can end up feeling neglected. In relation to this, while there is a growing literature on the psychological adjustment of siblings of children with cancer most accounts of the experiences and support needs of siblings of children with cancer have been derived from either parental or professional viewpoints, rather than by asking the brothers and sisters directly. Our work within this strand of the research project was designed to listen to children's and young peoples' accounts of their experiences and to inform the development of family focused resources.

The concerns of siblings (aged over 8 years) were:

- Being left out of conversations.
- Not understanding a word that anyone was saying.
- Questions on the condition - how to fight it? Is it common? What is normal? Whether it comes back?
- Fear over whether their affected sibling would die
- The meaning of their experience in terms of faith/loss of faith.
- Other people's reactions to their brother or sister
- Knowing about how other families coped with it, and how it affected them.
- Things that they did not want to ask mum or dad because it would upset them.
- The chance to talk to another sibling who was going through a similar thing

Siblings also commented on positive aspects of their experience, including their valuing of relationships and increased empathy/understanding of others' lives.

8. Can children use compensatory head movements after unilateral enucleation?

If a child has undergone a unilateral enucleation, to what extent does this impact on their ability to pick up information on the side of their affected eye? This study looked at the extent to which children were able to make compensatory head movements by turning their head around to access information on their affected side. Our preliminary findings showed that in the context of a familiar situation (e.g. sat playing with parent at a table) the children in our study *were* turning their head more when the information was on the affected side than on the unaffected side. Although these preliminary findings are encouraging, they only tell us what happens in a non-hazardous situation. What remains unknown, is the extent to which children also adapt in faster pace, dynamic situations like negotiating streets, crowded spaces and in playing boisterous games. We are currently looking at whether age, time since enucleation, or age at enucleation affects children's tendency to make this adaptation. In the event that we find that children are unable to do this, intervention studies could be designed which aim to reduce the risk of accidents.

9. Children talking about a 'poorly eye'

What sense do young children make of the reason for the loss of their eye(s)? Children aged between 3 and 6 years who had undergone at least one enucleation under the age of 28 months gave explanations in a play context for a toy's poorly eye like "his eye is dirty", "a hurting eye" or "needing a new eye". Children enucleated over the age of 28 months, made references to "bad eye" "the tonsil is making the eye wrong", "sore eye", "nasty lumps" or "little bad cells". Finding opportunities to find out what children understand of think their eye(s) are affected gives relatives and teachers the chance to 'nip in the bud' any misconceptions, which might in the longer impact on their self-understanding, confidence and self-esteem.

10. Living with an artificial eye: A family perspective

Our study showed that initial parental reactions to the appearance of their child's prosthesis were positive:

> *"When X actually had his artificial eye put in, I couldn't believe how good it was, I really couldn't, I had an overwhelming with gratitude to the artificial eye clinic."*
>
> *"Living with an artificial eye early on made her look a lot better, and that was a positive thing, enhances her whole appearance.*

We also found that parental reports of their child reactions were favourable:

> *"X was quite excited; she kept looking in the mirror."*
>
> *"She was like beaming, she was beside herself because it looked completely normal."*
>
> *"She was really pleased, she wanted to go and show everybody, she couldn't wait to go to school on Monday."*
>
> *"He just kind of like accepted that he had an artificial eye, he didn't behave any differently."*
>
> *"He actually didn't react like we expected him to. We thought he would actually realize that there was something there, but he didn't he didn't at all. He never put his hand to it, nothing. He didn't react like we thought he would."*

Given the low incidence of Retinoblastoma, and the lack of easy access to others in the same situation, some parents of children new to wearing an artificial eye may want to find out how more experienced parents felt:

> *"That was quite daunting, not knowing you know how and whether you were going to hurt her by touching her. I mean, you're always brought up to think that your eye is such a delicate area…so to be removing something from that region, it just seemed so wrong and alien and you're terrified that you're going to hurt something."*

> *"It was alright…a little bit apprehensive about taking it out ourselves, but once I got the hang of that everybody was fine including X. It's just the initial stage of taking it out and popping it back in. What to expect behind it that's what I didn't know…you imagine a gaping back hole, but it's not."*

Some parents have made suggestions of ways to develop resources for new parents coping with the task of inserting or removing the prosthesis:

> *"I don't know if they made anything that you could practice on apart from your child, so that you become adept at doing it. Invariably when it's your first time you are very cautious. I know I was very cautious, and it used to take ages, and then X would get really upset because it was taking such a long time. If you could do it in and out . . . so much less pain and stress."*

> *"Dino is brilliant at showing children what to do, but when we have dummies doing CPR, or anything like that, perhaps something could be designed like 'this is what you can do', rather than just faced with the child and the leaflet, something a bit more practical, a little bit more hands-on that you can play around with, that you can say, Oh . . . that no-one is going to scream, and punch you, or hate you for the next hour . . . cos you can actually have a go. As I said Dino's great for what it's designed for, to help the child understand, but I'm finding now that I'm using it to move Dino's eyelashes out of the way to get it in now, whether it could be something like a' girls world', one of those heads."*

What advice do parents offer for other parents in relation to the insertion and removal of the prosthesis?

1. Getting into the right frame of mind

> *All I'd say is it's just like helping them on with their jacket, it may look different but in theory you're doing the same thing, it's just assisting your child to do something different, but it will become normal…you put in, you put the eye in and nothing's going to happen… And you're not going to hurt them."*

> *"Just be very calm about it, and try not to be too nervous because I think your child does tend to pick up when their parents are feeling nervous, and then they will start feeling nervous. And also not to be afraid of it really."*

2. Practical tips

> *"Having somebody there to help you I would say as well, if you, if it's possible…two people, one to hold the child and one to actually take the eye out."*

"Make sure that your hands are clean…Make sure that the socket is clean and intact before it goes back, because if it's splintered at all, you're going to have major problems with the socket."

"Make sure there's two of you and everything ready. Don't just take the eye out and then go wandering off. Get everything that you want, your sterile water, some cotton wool or whatever to clean the socket, have everything ready and do it as quickly as you can. This just cuts down on the stress really."

"I don't use any of the tools to get it out with that they give you at the hospital, I have to really clean my nails and I have long nails. And I use my little nail on my finger, just to pull down and hook and once I've got the hook, you can actually push the eye down with your finger using the eyelid and so you're not actually touching, you know, the bulk of it, sometimes you know it's very difficult the first few times, because X you know, he'd had so much done to it, to them, that you know the thought of needles must be in their head. You know it's like an imprint…and you've got to get over that."

"You've got to find the position as well, and your child is comfortable with. X's favourite position used to be lying on the floor, and it used to go in from this angle, from head in that way, because you could hang over and you could see what you were doing, but we've found now she likes seeing what she's doing as she's got older. She can see what's going on now so we find it's a lot better. We're finding now that she really wants to see what's going on, but because she thinks she's the only one doing it, as I say I wear contact lenses, so we have a game now where I take my contact lens out so she can see it, and I've got her eye. She'll attempt to put my contact lens in which absolutely crucifies me but I think for what she's had to go through I can bear it, and I'll put her eye in. Now because she's doing it to me, she has to move my eyelashes out the way and everything . . . same thing."

"The way we've done it I think is because of the way that the clinic showed us is quite handy, she sits on my partner's lap because she gets her head quite far back, I find if you get them to look quite high up into the ceiling as they roll their eyes back it tends to widen their eyelids open a bit more. Almost at the bottom of the eye to lift, to lift the bottom out first. Lift up then the eye seems to fall from the top lid."

3. Treating it as a routine

"And it's talking about it all the time, so in the end you're talking about it, and they don't want to talk about it, because they're sick of hearing it…Do you know what I mean, 'Yeah, yeah, yeah.' That's how you've got to do it, so it's nothing, it means nothing – like cleaning their teeth…But it's a long journey and it's a hard one, cos you don't want to hurt them."

"Keep doing it, don't leave it . . . that's the biggest mistake we made. You've just got to be . . . consistently do it . . . in and out . . . so it becomes normal and the child's not scared of doing it. The longer you leave it the more awkward you are at it, the harder it is for them."

"Persevere, and get into the routine of doing it very regularly so the child gets into the routine as well, because early on we were doing it sort of once a week, and it was coming up to that time we would have this big fight."

4. Praising and motivating

> *"When daddy used to come home from work we used to say, 'Oh you'll never guess what X did today.' And he'll say, 'Oh I don't know.' We say 'He let met me take his eye out and wash it.' He'll say, 'You didn't did you? Oh that's a really good boy that is, what a brave boy,' you know and that used to make him feel really good"*
>
> *"We normally try and have like a little reward for him, maybe a little toy or some sweets. Get them motivated."*

As the ways people talk about a prosthetic eye can potentially influence a child's grasp of what a prosthesis does and how they feel about it, it is important to look at any issues involved in talk about a prosthesis with a young child. In the case of children affected unilaterally, they start to understand that although one of their eyes looks like an eye it actually does not function as one. Such comprehension is presumably counter-intuitive because according to their ongoing experience, they can still see. Many children are fitted with a prosthesis around the time of their second birthday, which also happens to be around the time when children start pretending and using the word 'pretend' in their play routines. This is highly relevant because some service resources aimed at children refer to the prosthetic eye as a 'pretend eye'. However, children's pretense normally involves the *temporary* use of an absent object (giving a doll a dose of imaginary medicine), the *temporary* substitution of one object for another (e.g. a box becomes a car) or, more popularly, the use of a *smaller* replica object to stand in for a "real-life" one (e.g. a toy pan). It is relevant that none of these hallmarks of children's pretense apply to the prosthesis. That is, a prosthesis *in situ* closely resembles a real eye, it is not absent and is the same size as a real eye. Further, as children often mark pretend activities in a 'let's pretend' to signify the end of reality, this 'temporary' flavour does not apply to the eye which permanently does not function. So, although the word 'pretend' would seem a highly suitable choice from the point of view of not labelling the prosthesis in a negative way, more research is needed into whether referring to the prosthesis as 'pretend' may not necessarily be optimal in aiding children to 'make sense' of the complex reality of not having vision in one eye. The quotes below from parents capture their thoughts about this issue:

> *"We never call it a pretend eye though, cos that makes it seem as that its not real, but it is real, and its not a game either, its real for these children but you don't want to frighten them off too much. Its difficult, but I would never call it a pretend eye."*
>
> *"Yes we've had this conversation and she said that she could see through it… and I said 'No you can't,' it's not a real eye it just looks like a real eye."*

Let’s now look at the diversity of ways families referred to their child’s prosthesis. In cases where children are unilaterally enucleated, parents reported differentiating between their child’s prosthetic and real eye which presumably helps the child to be able to distinguish between their two eyes when trying to remove and insert their prosthesis. As Table 8 shows, the most common references used involved making the distinction between ‘bad and good eye’; ‘pretend eye’ and ‘good eye’. Some parents of unilaterally affected children did not use two labels, and in these cases, the terms ‘pretend eye’ or ‘special eye’ predominated.

Table 8 How parents differentiate between the prosthetic eye and other eye

	No. of parental responses	**%**
Parents who differentiate:		
Poorly eye vs good eye	1	4.2%
Poorly eye vs eye	1	4.2%
Bad eye vs good eye	3	12.5%
Pretend eye vs good eye	3	12.5%
Pretend eye vs real eye	1	4.2%
Pretend eye vs eye	1	4.2%
Magic eye vs eye	1	4.2%
Artificial eye vs real eye	1	4.2%
Hard eye vs real eye	1	4.2%
Other eye vs good eye	1	4.2%
Parents not differentiating:		
Pretend eye	3	12.5%
Artificial eye	1	4.2%
Special eye	3	12.5%
Eye	2	8%
Other responses:		
Child too young to know	1	4.2%
Total	**24**	**100%**

Another issue affecting families is that in our study parents reported the situations where their child was making discoveries about the status of their own sight loss. These situations may help the child begin to grasp their visual status, and what it means in practice:

> *“He puts the binoculars to his eye, and he puts them there and he thinks there’s , . . . we’ve done it several times to try and make him aware that he can’t see out of the eye. Cover that eye, and then cover the other eye over to try and make him aware. He found it quite surprising that even though I covered one eye and then the other eye, I could still see him, and he didn’t really believe it fully. That’s what made him aware. We did that game quite a few times, and I don’t really think it sunk in the first time. This was not that long ago . . .when he was 3 or 4.”*
>
> *“At the very beginning was when he thought he could see through his eye, he was actually quite shocked when he couldn’t.”*

> *"She realised the other week that when she covered up her eye what works a little bit - that she couldn't see anything out of the eye what doesn't work. She'd covered that one up and said, 'I can't see nothing now, but now I can.' …It's like it was a game it just, you know I suppose a little bit of a turning point that she's realised."*

A number of parents reported children being curious about the eyes of others. Again, this may aid them to make sense of their visual status:

> *"She has asked the question 'why do I only have one eye?' She's asked the question 'what's it like to see with two eyes?'. That's about it, I don't think she remembers how it looks with two eyes."*

> *"I think she'll sort of say, 'everybody is different Mummy'. Will <name of sibling S> have to have an artificial eye? She has said that because he goes for his checks, she says 'will S have to have an artificial eye?' When she says, 'am I the odd one out', I just say there are other children have got artificial eye as well. The newsletter that comes through I sometimes show her the odd photo. Some people have to have both eyes . . . really . . . so she said 'they wouldn't be able to walk they would have to have a wheelchair wouldn't they?' Well actually you can learn to ride a bike and get around and read. She'd convinced herself to have a wheelchair. Sometimes about the colour. Sometimes said her eyes aren't the same colour. In different light sometimes its slightly lighter or darker."*

Some parents reported their children commenting that meeting others like themselves would be desirable:

> *"X expressed a wish to go to family days to meet other children and to talk to them, and maybe ask some questions. In the run up to family days she said, 'I can go to family day and ask that' and she's wanted to meet other children with artificial eyes."*

> *"When we went to the Rb society at the annual day in Birmingham last year, the first time he's been old enough to realise that other children the same age, that was when we pointed it out to him that you're not the only one, you look at these boys and girls are all the same a you."*