

*NOTES ON BLINDNESS*

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*NOTES ON  
BLINDNESS*

A Journey through the Dark

JOHN HULL

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## *A Note to the Reader*

This book was first published, as *Touching the Rock*, by SPCK in 1990, and was reissued in a new edition in 2013. This 2017 edition, published by Wellcome Collection and Profile Books, follows the success of *Notes on Blindness* (2016), the award-winning documentary adaptation of *Touching the Rock*.

# *Introduction*

Cathy Rentzenbrink

Why do we read? Sometimes I'm looking for comfort, consolation, distraction or entertainment. Other times I'm seeking to learn new things and to walk a mile in another's shoes. Perhaps especially when I read memoir, I want to understand and know another human being through the rendering of their world. On rare occasions, all of the above pulls together and I enjoy a deep sense of satisfaction that not only has my reading time been well spent but that I am somehow changed, that what I have learned has shed light on my own journey through this extraordinary life. *Notes on Blindness* satisfies all these readerly desires and is a beautiful example of how the best books are simultaneously intensely specific but have universal meaning.

John Hull was an academic and theologian who was registered blind in 1980, around the same time as the birth of his second child. Initially he was preoccupied with the excitement of problem-solving and discovery as he figured out how to live and work. It was three years later as the last light sensations faded and he travelled further into what he calls 'deep blindness' that he began recording the observations about his life that form this book on audio cassette, charting the progression from being 'a sighted person who could not see to being a blind person.'

This is a practical as well as a metaphorical journey. Hull can

navigate himself between home and work very successfully using his cane and the hazards he encounters are more often human than object. He observes how tricky it is for a sighted person to understand that the cane is a tool to enlarge his field of perception, not something he wants to lean upon for support. It is a seeing stick rather than a walking stick, but aspiring helpers will grab and point with it, failing to grasp that he can't see what they are doing. Not everyone is so well-intentioned. There are taunts from unknown men in the street who shout about imaginary cars or accuse him of being a fraud. What feels perhaps more shocking than this random cruelty is when acquaintances tease him by wanting him to identify them by voice, rather than sensibly introducing themselves. These silly games make Hull feel like he is in the middle of a game of Blind Man's Buff.

Human connection is based on reciprocity but, of course, Hull still wants to be fully seen even though he can no longer see. He tells us about becoming disabled, feeling that he has lost part of his manhood and part of his humanity. He often finds himself being discussed as though he were a child as people ignore him to ask his wife what he wants to do.

What is it like to no longer see the workings of time upon one's face, or the faces of loved ones? Hull is distressed when he can no longer conjure the image of his wife or his eldest child in his mind's eye. He has never seen the younger ones. Surrounded by children at a birthday party, Hull realizes that he doesn't know whether the child happily scrambling about on his lap is his own, and can't work out how to ask.

As Hull continues to contemplate the curious nature of his new life, a portrait emerges of a warm, intelligent and reflective man trying to make sense not only of *his* blindness, but of blindness itself. Work and new ideas are central to Hull's wellbeing, to the extent that even a single day away from study leaves him less able to grapple with despair. He can't write a stoic or

matter-of-fact book, he tells us, but his quest for understanding will help to keep him sane.

Hull's observations on the central question of his attitude towards his blindness are very relevant to coping with any sort of adversity that sees us in the presence of a reality we wish to refuse. Here he poses the dilemma: 'If I were to accept this thing, if I were to acquiesce, then I would die. It would be as if my ability to fight back, my will to resist were broken. On the other hand, not to acquiesce, not to accept, seems futile. What I am refusing to accept is a fact.'

Towards the end of the book Hull finds a middle ground between the stark binaries of acceptance and rejection. He calls this 'integration' and it leads to another stage on the journey: 'As one goes deeper and deeper into blindness, the things which once were taken for granted, and which were then mourned over as they disappeared, and for which one tried various ways to find compensation, in the end cease to matter. Somehow it no longer seems important what people look like, or what cities look like ... one begins to take up residence in another world.'

Where once Hull might have appreciated a pretty church, now he is flooded with joy at the sound of the bells. He can tell whether a light is on by lifting his face to it, notes that his skin has become more sensitive to changes in the wind and the sun. He begins to think of himself as a whole-body-seer: 'A blind person is simply someone in whom the specialist function of sight is now devolved upon the whole body, and no longer specialised in a particular organ.'

Is there meaning to be found in the blindness? Often people ask Hull about the workings of providence and he is sanguine about the accidental nature of his situation. Born in an earlier time, he'd have lost his sight sooner, born in the future, it may well have been saved, but we can transform the accidental events of our lives so they carry purpose: 'The most important thing in

life is not happiness but meaning. Happiness is the product of chains of accident which tend towards our well-being. Blindness does not make me happy. I did not choose it, nor was it inflicted upon me. Nevertheless, as an accidental event it could become meaningful.'

John Hull died in 2015. He is survived by his five children and his widow Marilyn who has written an epilogue for this new edition. There is wisdom on every page of the finely wrought piece of self-interrogation he has left behind. These dispatches from the dark but also from the light will stay with me a long time. What a gift it is to the whole of humanity when one person writes with honesty and clarity about the way they experience their world.

# *Preface*

John M. Hull

In reading this book, you probably want to understand blindness better. You want to know what it is like to go blind, and to be blind. A couple of years after losing my own sight, I became interested in blindness and read more than twenty autobiographies of people who had gone blind. These stories amazed me: they were often full of humour, courage and ingenuity. Some told of how they became golf champions, ski experts, medical practitioners and successful business people. Some were written to proclaim a faith, others in the spirit of stoic acceptance. Most of them were inspiring stories of triumph and reconciliation. But I did not find what I was looking for: an account of blindness as I knew it. Maybe I did not look hard enough, or read sufficiently widely. All I can say is that the books I did read did not describe the aspects of blindness which were more significant to me. Many of them were literary accounts: they had a beginning, a middle and an end. They were like novels, with an interesting style, a climax or a resolution. This book is not like that.

In June of 1983, about two and a half years after I had been registered as a blind person, I began to record on cassette my daily experiences. This was when the truth of being blind began to hit me. You may wonder why it took so long, but the first couple of years were full of exciting problems to be solved. It was

only afterwards that I began to make the transition from being a sighted person who could not see to being a blind person. Sometimes I added something to my cassette every day, day after day, but sometimes weeks would go past. I recorded things that I felt strongly about; when they puzzled me, or delighted me, I said what I had to say in order to help me to grapple with what was going on. I kept this up for three years, and gradually the need to make further recordings grew less. I spoke about my children, my work, my relations with women and men, and I recorded my dreams.

This book is the result. It has no particular ending, because blindness has no ending. It would be nice to be able to say that there was a happy ending, that a miracle happened, but it didn't. I was interested in how my children would gradually discover what it meant to have a blind father. I was interested in what would happen to my dreams. I recorded my dreams, mostly on the day after the dream took place, sometimes within a few minutes of waking. The dream narratives form a sort of subplot, if it can be called a plot, since the conscious material shows how the unconscious mind struggled with the problem. The relationship between dreaming and waking and the nature of consciousness itself is one of the persistent themes of the book. Other themes are the changing perception of nature, the transformation in my understanding of what a person is, and the problem of making sense of such terrible loss.

The book is not tightly organised. There are bits and pieces all over the place. There are times when solutions seem to be in sight, so to speak, but there are continual relapses, when nothing seems to have been gained or learned. If there is repetition, it is because the same problems and the same experiences went round and round, interpreted from many aspects.

*To the blind reader*

Blind people differ from each other as much as sighted people do. I do not claim to speak for you, but only for myself. You do not need to know what blindness is like, because you are blind. Perhaps you are reading this book in order to discover companionship with someone else who has passed your way. I hope you find it here.

# *Sinking*

Summer 1983

*1 June*

How long do you have to be blind before your dreams begin to lose colour? Do you go on dreaming in pictures for ever?

I have been a registered blind person for nearly three years. In the past few months, the final traces of light sensation have faded. Now I am totally blind. I cannot tell day from night. I can stare into the sun without seeing the faintest flicker of sunshine.

During this time, my dreams have continued to be pictorial. Indeed, dreams have become particularly enjoyable because of the colourful freedom which I experience when dreaming. Has blindness, then, made any impact upon my dreams at all?

About six months ago I had a dream in which my sight improved. I could see my son Thomas. There he was, a cheerful, cheeky, lively little boy of two and a half sitting on my knee.

My final eye operation took place on 1 August. Thomas was born on 22 August. When I cannot quite remember how long I have been blind, I ask myself how old Thomas is.

Being present at the birth was a frightening but wonderful experience. They turned on the microphone of the machine which monitored the heartbeat of the baby. I could hear it very

clearly as I sat beside the bed. Marilyn and I had been married for little less than a year. The baby's heartbeat was incredibly fast, coming in little waves of accelerations, in time with the contractions. A lot of the time I did not know what was happening. Marilyn was crying. The bed seemed to be surrounded by midwives and doctors. There were a few quiet moments and then a baby's cry.

For about eighteen months I continued to have some visual impression of him. Within a few feet, I could tell where he was lying, and what colour his clothes were. I could tell the broad outlines of his face, when he was yawning or waving. All of the finer details were lost, the little expressions around the eyes, the shades of emotion in the early stages. In the summer of 1981, on the beach in Wales, I used to tie a piece of string around his ankle, so that if he crawled more than a few feet away I would be able to find him again. When he could walk, I used to play with him on the steps of the University Library. I could let him off the reins, because even if he disappeared I could hear the sounds of his shoes as he ran across the stone landings on those quiet, Saturday mornings in the winter, when the campus was almost deserted. Sometimes I would run after him in panic, frightened that he might get to the edge of something before I could catch him. As he became more mobile, and my sight grew worse, these outings became increasingly difficult.

### *3 June*

About a week ago I dreamt that I was returning by rail to a town in Normandy. I had an appointment to meet Marilyn in a restaurant which we had visited on a trip to Normandy which we made a year or so before our wedding. I left the station, and paused to examine the map to see where the station was, only to realise that I had left my white cane on the train. What worried me was not so much how I would get around, but the fact that

I had lost a piece of my property. I then found myself holding a long metal tube, the sort that is used to prop up a clothes line. I was using this to explore my path, and I noticed that the people in the area around the station were looking at me curiously.

This is the first time I have dreamt of myself as being a blind person. There are a lot of unresolved contradictions. It would be impossible for a blind person dependent upon a cane to forget to bring it with him. I wanted the independent freedom of movement which would make it possible for me to keep my rendezvous with Marilyn in the restaurant, but blindness would take this freedom away. So I had the white cane, yet I did not have it. I could not move without a sort of substitute for the cane, yet I could see the reactions of the people around me. I had lost something which I would need when I met Marilyn. Loss of the cane was not only the loss of my ability to find her, it was the loss of something deeper, potency, the ability to love her.

I began to carry a short, white cane early in 1980, mainly as a signal to traffic when I was crossing the road. When my sight got worse, I bought a slightly longer cane, and then a longer one still. Finally, I bought a full-length cane, five feet long, with a rounded crook on the handle. I never seemed to have the time for any mobility training, although occasionally I wondered if I was developing bad habits in my technique, which could have been avoided with some formal instruction.

On the whole, my experience has been that, if I have a bad habit, it causes me some inconvenience or inefficiency in my movement, and is naturally corrected in the effort to move more freely. In other words, blindness itself imposes an iron law upon the user of the white cane. Lampposts, kerbs and stairways are the best teachers.

*5 June*

Sometimes when I greet people by saying, 'Nice day!' they remain unresponsive or even appear surprised. The idea of a nice day is largely visual. A nice day occurs when there is a clear, blue sky. The sun will be shining and it may be reasonably warm, although even a bright clear day in the middle of winter will be called a 'nice day although a bit nippy'. A sighted person would not call it a nice day, let alone a lovely day if it were overcast.

For me, the wind has taken the place of the sun, and a nice day is a day when there is a mild breeze. This brings into life all the sounds in my environment. The leaves are rustling, bits of paper are blowing along the pavement, the walls and corners of the large buildings stand out under the impact of the wind, which I feel in my hair and on my face, in my clothes. A day on which it was merely warm would, I suppose, be quite a nice day but thunder makes it more exciting, because it suddenly gives a sense of space and distance. Thunder puts a roof over my head, a very high, vaulted ceiling of rumbling sound. I realise that I am in a big place, whereas before, there was nothing there at all. The sighted person always has a roof overhead, in the form of the blue sky or the clouds, or the stars at night. The same is true for the blind person of the sound of the wind in the trees. It creates trees; one is surrounded by trees whereas before there was nothing.

The misunderstanding between me and the sighted arises when it is a mild day, even warm, with a light breeze but overcast. To the sighted, this would not be a nice day, because the sky is not blue.

I will have to make my comments about the weather more specific. I must remember to say that it is nice and mild today, or that it is a pleasant breeze.

*8 June*

Last night I had a beautiful, refreshing dream, in which I was walking along a river valley. There were fine homes, holiday bungalows, built along the river bank. I was on a walking holiday. I experimented, looking this way and that, finding out if I had sufficient range of sight to take in the whole of the valley and the landscape. Although it was not perfect, I found that I could get a sufficient sense of the place to move freely and to enjoy the scenery. I was saying to myself, 'There you are, you see! In good light and in these conditions you can still manage fairly well.'

In 1976 and '77 I could still see well enough to enjoy going for long, solitary walks in the Worcestershire and Shropshire countryside. The Severn Valley was a favourite walk. I used to go by bus or rail. Getting on the right bus was a problem. I could go into the coach station in the city centre and find the exact bay for the bus I wanted, or I could stand at the bus stop near my home and stop every bus that came along, asking the driver if he was going my way. I tried to make out the numbers of the buses by using a little telescope, but often the bus was upon me before I could work it out. Reading the maps was still possible with magnifying glasses. I liked walking beside the river, because it was almost impossible to get lost, although it was necessary to pay fairly close attention to the ground immediately in front. I often used to say to myself, 'Provided it doesn't get any worse, I can still manage.'

I have been having that thought for at least ten years. I could still manage, provided it did not get any worse. Even after I was registered blind, I could work my way from the office to my home by following the bright, double yellow parking lines painted on the edges of the University roads.

I would still be alright, if it stayed like this. When it got worse, I could still get home at night by following the street lamps one by one. I felt like a sailor far out at sea on an inky, black night,

with one star to guide me. When I reached the lamppost, I could dimly make out the next little light. I could still manage, provided it didn't get any worse.

My dreams seem to be lagging about six years behind reality.

### *21 June*

During the first couple of years of blindness, when I thought about the people I knew, they fell into two groups. There were those with faces, and those without faces. It was a bit like wandering round the National Portrait Gallery. Here are rows of portraits, but here is a blank. You can tell where it used to hang by the outline of the wallpaper, and beneath the space is a little label giving the name. Perhaps this portrait is on loan elsewhere, or perhaps it is being repaired.

The people I knew before I lost my sight have faces but the people I have met since then do not have faces. I used to find the contrast between the two groups of people disturbed me. I could not relate one set to the other set. I knew how I knew the first lot – by their faces. How could I ever feel that I really knew the second lot?

As time went by, the proportion of people with no faces increased. Whole rooms are now bare, and the portraits which remain are covered with dust. Is it possible that some day I will come to visit the gallery and find the door locked, with a notice which says, 'This exhibition is permanently closed'?

It is three years now since I have seen anybody. Strangely enough, I have fairly clear pictures of many people whom I have not met again during these three years, but the pictures of the people I meet every day are becoming blurred. Why should this be?

In the case of people I meet every day my relationship has continued beyond loss of sight, so my thoughts about these people are full of the latest developments in our relationships. These

have partly covered the portrait, which has thus become less important. In the case of somebody I know quite well but have not seen for several years, nothing has happened to take the place of the portrait, and when I think of those people, it is the portrait which comes to mind.

It distressed me considerably when I realised that I was beginning to forget what Marilyn and Imogen looked like. I had wanted to defy blindness. I had sworn to myself that I would always carry their faces hidden in my heart, even if everything else in the gallery was stolen.

If I do want to recapture the face of someone very close to me, I do it through visualising a particular photograph, an actual photograph that I can remember very clearly from my sighted days. When I try to conjure up the memory of a loved face, I cannot seem to capture it, but the straight edges of the photograph seem to fix the mobile features firmly in my mind, so that I can imagine myself gazing at the image. Some people tell me that this is a happy situation. I will always remember Marilyn as being young. She need never be troubled by the thought that I will see her getting older. I am not so sure about this, since I find it hard to believe that ignorance can ever be better than knowledge.

The difference between those who have faces and those who do not becomes more poignant when I think of my own children. I have a lot of visual memories of Imogen, now aged ten, mostly based on photographs, but with the occasional vivid life situation thrown in. I have only a few rather vague impressions of the face of Thomas, now nearly three, which are based upon the first six or nine months of his life, while I still had a little residual vision. Of Elizabeth, now sixteen months, I have no visual images at all. The place on the wall which should carry her portrait is completely blank.

What difference does it make? I am not aware of any