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Abstract

This is an excerpt from a book which describes the various stages of adjustment parents of children with disability usually go through. It quotes other parents and discusses the emotions with sensitivity and understanding. The final comment sums up the gradual shift to reality - "the whole process of grief is growth. Growth and learning from the experiences. It is a process of change and what we do with it is up to us." **Keyword: Families**

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TAKING ON THE WORLD

Empowering Strategies for Parents
of Children with Disabilities



New York and London

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1 Shock and Panic

Fight or flight. 'Let me out of here.'

In crisis the autonomic nervous system reacts immediately by short circuiting conscious thought. This primitive reflex prepares us for fight or flight. The initial body response affects blood pressure, heart, and breathing rates, and stimulates muscle activity via adrenal flow. After a short time there is a secondary response as we attempt to put this activity under conscious control.

During the initial 'panic' response we experience the overwhelming drive to run away or to hit out. When we recover deliberate control we often regret how we reacted at the initial shock, but it cannot be helped as it is not behaviour for which we were responsible. People heightened by panic have also commented on sensitivity to smell, hearing, and taste. Apparently panic has the effect of making us more aware of primitive animal senses so that we can escape or attack if threatened further.

Fear plays a significant role in this panic stage. We fear that we may not be strong enough to survive the crisis. As we experience these self-doubts there are internal chemical and electrical interactions surging through the body causing such by-products as nausea, fainting, and not infrequently, violence. Activity follows arousal and excitation. The brain is flooded with messages which urge us to escape either by fighting our way out or by running away.

You will notice how frequently parents mention their physical reaction with words like: 'explode,' 'run away,' 'shout,' 'wander,' 'smash,' 'screamed,' 'kill myself,' 'got drunk,' 'self destruction,' 'burst out crying,' and so forth.

In almost every report there are instances of actual body

involvement. A parent recently made the comment that the worst part was that there was a compulsion to run away, but circumstances were such that this need could not be obeyed. That energy was frustrated and diverted. It resulted in days of diarrhoea. The body was saying one thing, but circumstances demanded another: the energy settled elsewhere.

I have heard people talk of an acid or metallic taste of fear or panic. Another person reported actually seeing red. We say that we see red when we are angry, but this man 'saw' red in panic.

All these responses may seem bizarre, but they are human.

Cheryl: The feeling of shock experienced when told my eight-month-old baby would be a vegetable cannot be described. My head seemed to explode. All I heard was that I could expect nothing. They advised me to put the child in a home and forget about it. The bottom fell out of my world. I thought I would either faint or be sick.

Sheilah: Shock. You ask about shock. The child is six years old and I'm still shocked but initially I wanted to run away, just to run and run. It was devastating. I kept shaking my head and saying it's a bad dream, then a day or two later I kept saying 'Why my baby?'

Kevin: Well it sounds chauvinistic, but the shock was that my son was retarded. Of course that may have been a shock reaction because we didn't care if we had a girl or boy. Then I got a picture in my head of how the families would react and believe me, they were deeply shocked. Each member acted differently with reactions from stunned silence to tears.

Helena: As the doctor was telling me I kept saying in my head 'that's a lie!' When the doctor put a hand on my lap I shouted, 'Don't you dare touch me you wicked person.' Isn't that cruel of me... but I could not cope with the scene.

'Oh no! Not my baby.'

2 Disbelief

As one of the parents commented, how can anyone believe their child is handicapped. Absorbing that reality takes time. Most people are immobilised with fear about their capacity to survive under the changed conditions. They feel stunned and confused. I notice facial expressions change when this stage is discussed. There is a look of bemusement as though they are trying to figure out how this awful thing happened to them.

Disbelief is generally experienced in the early stages of grief. Coincidentally, this is also the time when parents are trying valiantly to cope with the stress of their changed circumstances, as well as seek out all the available information about the services they require. The result is total disorientation.

It is therefore terribly important that at this stage parents receive practical advice on such topics as child management, social security allowances, and the names and addresses of suitable organisations that provide therapy for their child.

If professional staff can appreciate these parents simply do not have this information at their finger tips, and can smooth the way for them by organising appointments and offering alternatives, then parents would not suffer the agony of the confusion stage which follows.

Jayne: How can anyone believe their child is handicapped. That only happens to other people never to you. Of course I disbelieved it, denied, and disbelieved all at once. I don't know, but you don't expect a brain damaged child do you? All I did was to check that all the toes and fingers were there.

'I cannot/will not believe it.'

It seems to me that some of the parents made deliberate efforts to deny what they knew to be true. There is a need to resist the truth in a vain attempt to retain the familiar. Well-intentioned relatives often encourage this reaction. Perhaps they too are uncomfortable with the reality.

Occasionally there are individuals who prefer straight confrontation. These are the 'call a spade a spade' personalities. Most people, however, cannot cope with the full picture in one sitting. It is best to tell these parents the story in instalments in case the full truth destroys them. The important point to remember at all times is that the parents have the right to all the information they feel they are able to cope with.

For professional personnel this is an area fraught with danger because it is difficult to identify who can cope with all the information at one time and who cannot. Usually it is the doctors who face this dilemma, for they are the ones who are equipped with knowledge to diagnose the child.

It is not readily recognised that a genuine problem for doctors is that little is known about the effects of some conditions, therefore, doctors may not be fogging or avoiding the question—they may not know the answers.

Dawn: The worst part about denial is that when your child looks normal you can fool yourself. You tend to go out seeking people who reinforce this. You know the sort, the ones who say everything will be okay, the child will outgrow it; or 'the professionals make mistakes all the time.'

4 Confusion

'What can I do, where can I go?'

This is the period when the parent is trying to make order out of chaos. After months of tests, clinics and interviews there is the assessment. The assessment is carried out in order to place the child in the most appropriate place for its disorder. However, for the parent it can be a harrowing experience. The parent may come to the assessment confused and leave it feeling even more confused and depressed as well. I believe that this is because the decision making has been taken out of their hands. They are not consulted, only told about the experts' decision. The people who conduct the assessment are certainly well-intentioned, but they do not include the parent in the discussion at this stage. Parents are often given alternatives, but because they have not been included in the preliminaries they may not be convinced about the suitability of the referral.

Several parents mention that mental retardation was not discussed prior to the assessment. That seems a serious bungle, for how can they make such an important choice for their child unless they are aware of the intellectual prognosis?

Without doubt, mental retardation is the handicap which is most difficult to accept. In this chapter you will read how distraught this prognosis makes a parent feel. The terminology used by professionals to describe the handicap often needlessly confuses the parents. You may doubt that a professional person would use the word 'vegetable,' but this has been done. You can imagine how the parent is demolished by this term—all those shattered dreams and hopes dashed in one swoop.

5 Despair

Eric: Before this happens to you, you think experts know everything, then you find they disagree. They either are liars, incompetent, or cowards. I don't know which, but whatever it is, it is confusing. From being told the child is a vegetable you get, 'Don't be silly, daddy, your baby's okay.' What do you believe? Who do you believe?

Margaret: What about that run around? Confused, yes I was confused. Do the experts think you've got nothing else to do? Days sitting around in clinics; catching half-heard phrases; never speaking directly to you, only to another staff member.

Heather: When I did ask questions the inference was that I should know the answer or that I had no right to ask it. It was obvious that something was worrying them, but they would look at me as though I was stupid.

Felicity: The worst moments of confusion were when I was summoned for an assessment. I didn't even know what that meant, it sounds such a horrid word when you don't know its meaning. I thought it very strange that they took a picture and then conducted all the other tests. No explanations: just go here, go there, sit and wait there.

Magda: I always felt so stupid. There were so many questions I couldn't answer. I must have sounded confused because I was. I was new to it and I didn't know what they wanted from me.

Cathy: We went to this place and there was no one to soften the blow. There were no kind words. We were given a coffee but even that seemed due to regulation rather than thoughtfulness. It was an awful experience.

Paul: No one is consistent. Perhaps I felt frustration rather than confusion, but the frustration came from the confusion of medical opinion. Everyone said something different, in prognosis, in medication, and they still do. No one seems to know. It changes all the time.

Angela: I still haven't got an accurate diagnosis of my kid's condition. From saying he is profoundly retarded, I've been told, 'Mummy, don't worry. He's only deaf.'

'I can't cope.'

By and large the overwhelming emotional response to the confusion phase is a gut reaction of festering panic. Many parents expressed a sense of being trapped, and all gave vent to feelings of disappointment, shame, embarrassment, and similar self-defeating emotions.

The parent who expressed this period as all 'dead ends' may have caught the feeling in two words. It is a time when progress seems to stop and depression sets in.

Douglas: I keep saying, 'Why my child?' That makes me desperate. I wonder, Will I cope? What did I do? Did I deserve to be punished? Does the child deserve to be punished, to suffer like that? I guess this is when I feel despair or is it guilt! No, I won't buy that, I didn't do anything wrong so I don't need to feel guilty.

Lisa: When I get a trapped feeling, I feel desperate. How long will the trapped feeling last—months, years, or forever!

Jayne: I've looked into the alternatives, but I chose to put them aside for now, because I am coping, but if I think of the future I feel desperate.

Colin: Despair is a frequent experience for us. With two mentally retarded children, we have to face that management will possibly get more difficult as we get older.

Magda: My worst moments of despair are not when I am home here with my child, they are when I see the disappointing reactions of our families. In denying the child's handicap after all this time, it is like a rejection of me as a person and of their grandchild.

6 Anger

'Why my child?'

We all experience anger, don't we? We all know feelings of frustration and rage when we are angry, that nauseating energy which churns away in the stomach when some occurrence arouses wrath.

Unfortunately, societal attitudes frown on expressing anger, therefore there is a general trend to mask it. Often it is kept down and turned into depression and anxiety making us feel helpless.

I encourage open expression of anger because unless it is ventilated it is self-destructive. We have the right to express anger to the person it is directed to, but frequently many factors prevent it. At times the anger is at bureaucracies and institutions, or a person we will never see again. It can be at events rather than persons, or at ourselves because we are not handling things the way we would like. It can be directed at a mass of people and events and be the result of a build-up of small irritations which hinder the free open communication so necessary for defusing the anger.

If the parent can identify the emotion, recognise the cause, work out appropriate courses of action, and then assertively deal with it, then it will be dissipated. Many times the very exercise of exposing the roots of the anger is enough to rid it of its sting.

The essential thing is to accept that anger is a normal emotion and that, although we are taught to deny it, we cannot. It will not be denied. If it is, it will be transferred into another self-defeating feeling.

Peter: My wife and I had a lot of fights. They would be

over petty things. I'd blaze and then walk out. I don't know who I was angry with, certainly not my wife.

Penny: I would get angry at the hospital and all the bungling. There were times when I'd lose control and resort to sarcastic remarks about incompetence.

Christine: The greatest anger was at a social worker who five minutes after meeting us made statements that I would have a breakdown, and that the marriage would collapse, and that the children would be sent to a home. Everything said was negative. It was as though we were being knocked down. I was devastated, it was like losing all hope of survival. I nearly did have a breakdown actually.

Colin: I was so angry I was flabbergasted. For once in my life I could not speak. I was stunned. After asking for help, to have a social worker who was so negative was just too much. I was so angry I reported it to another organisation. Their social worker came out and he was marvellous. he always has been, right from the first.

Ann: I get aggressive when I get told what I'm supposed to be feeling. I hate it when a doctor tells me what I think and feel, as if they know what makes me tick. I am a coper and when I get treated as though I'm a neurotic. stupid female, I get angry.

Sheilab: Anger wells up in me every time I think of that doctor who is to blame. I know he didn't do it on purpose, that it was an accident, but I get angry just the same.

Sharon: I say I don't get angry about anything, but I now understand that depression can be a symptom of anger kept in. I have realised that I am angry and am now less depressed. I am angry that we were not told the truth right away. I am angry that professional people did not consult us before they did tests and things. I am angry that we were fed with half-truths and were given false hopes. I am angry with myself that I did not assert my right to demand clear answers to my questions.

Gillian: Anger. Oh yes. I have anger.

7 Depression

'Nobody cares because I'm worthless.'

anxiety, tears, aggression, irritation, frustration, sense of failure, rejection, sadness, regret, fear, isolation, self-destruction, and feelings of lowered self-worth are evident in each testimony. These are all the elements of depression. Also, parents say at times that they are not depressed, they are sad; this is an indictment of social attitude to depression. Too often we feel ashamed at being depressed so we rationalise it. Depression is real. It is also rife in our complex society, why then do we feel ashamed at our feeling?

It is essential that the depressed parent should feel able to become an active participant in the treatment of his or her child. He or she should also be encouraged to go out and participate in sports and fun, and to make new friendships and renew old ones. In short he or she should be encouraged to take action. Activity energises and stimulates and, ultimately, leads to optimism. There is a period when the depressed person *acts* as if he or she were happy. This follows immediately after the decision to take action against the depression. It is a kind of role play of being a happy, confident person, but it works. It may take a few trials, but after a short time the depression is dispelled. The individual is strengthened by the power he or she displays and this then leads to a more positive approach.

Assertiveness training is an excellent tool to activate the immobilised, depressed person. It equips the parent with the skills to confront the frustrations and barbs of various encounters with an appropriate degree of confidence and to assert personal rights. Assertiveness is not aggressiveness; it is a confident encounter in which all parties feel more aware of each other's points of view. When parents feel confident in the face of bureaucracy they have returned to a state of well-being. They are in control.

Ann: If someone said to me what difference has having a handicapped child made to you and asked for it in one word, I'd say 'depression.' I think that for three-and-a-half years out of four I have been depressed. I think I am not depressed now because I have permission to talk through all the painful emotions. This has relieved the stress so much that

~~I can now identify which I am and what I am feeling.~~

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Depression seems to be a state of lowered energy. It can be recognised by body language, verbal expressions, and general attitude. The depressed person frequently has drooping shoulders, tentative eye contact, a hesitant approach, and is usually slower in speech than normal. He or she also has an expectation that things will go wrong, and is often needlessly worried and anxious. People in this state feel dejected and worthless and often cannot understand why anyone can be bothered with them. They can be difficult to make meaningful communication with because of their retreat.

The ability to conquer depression seems almost impossible to a person in such a state. Changing direction and getting things under control require energy and confidence, both of which the depressed person lacks. When coming out of a depression, a person may appear to be, or be, hostile. When this hostility surfaces there is little understanding on the part of anyone else that it is usually a valiant attempt to overcome depression. If this hostility is met with hostility, then the person may retreat back into his or her shell. However, if the hostility is met by someone with an awareness that it is a passing phase, then recovery can be attained.

Sometimes people become depressed for so long that they forget what they were like before it happened. Perhaps they will never be exactly that other personality again, but in reality they are all changing all of the time. Therefore, when there is an anxiety about this, it is important that the parent feels optimistic about being able to make positive changes.

You will observe from the following statements that

9 Gradual Shift to Reality

'I'm learning to live with it.'

It seems that by the time parents get to this point in regaining their equilibrium they have dealt with the hurt. They are not so sensitive to other people. They are in control of their own lives and learning to make compromises.

Reality has become bearable and much of the drama of crisis has passed. I call this 'the business as usual' time. If all has gone well a couple's relationship will have survived the trauma. They will have taken up either past activities or compromised with new ones. They will have dealt with the helplessness; have become resigned to the new life style with its new sense of responsibilities; and have grown and strengthened despite the disappointment.

A return to the basic essence of their personality will be apparent. Gone is the tentative, confused person who felt lost and bemused. Now the parents know what they want for themselves and the child. This is a move which is wholesome and positive.

Christine: Oh yes, I'm getting there, aren't I? I can now say my child is handicapped and quite often say mentally retarded. I bet you thought that would never happen. It has taken about a year. It isn't a competition, but does that make me fast or slow?

Colin: Since we have resolved the guilt and depression I think we can both say we are realistic. My wife got there sooner than me, but that helped me along. The good thing about it is that all the shame has gone. Now when strangers

say, 'Have you any children?' I can say yes and tell them about the condition in a relaxed way. Their responses differ, but on the whole it is usually, 'Sorry to hear that,' or 'Read any good books lately' type of thing.

Gillian: Oh no, I am not in what you would call reality because I refuse to put a tag on my kid until all other reasons have been disproved. To me that is reality, to you it would not be.

Donald: We had no alternative but to face reality immediately. With the child's condition being so obvious, there was no doubt. In reality the child needed immediate surgery; the neurosurgeon put us in touch with reality on that very first day.

Paul: I wasn't in touch with reality until we started the grief counselling. It was one long nightmare until then, but yes, I am into reality now. The hurt is less too, that is what is so good about it.

Mark: Remember when I said to myself, 'Why my child,' well, the time I answered myself and said the reverse, 'Why not my child,' that was when the clouds cleared away and I faced reality. From that time I was able to comfort my wife and really relate to the child. It was such a relief, you can't believe how that change in thinking eased the pain.

Bill: It was a long slow progress to shifting to accepting the awful truth, but I got there and it has been much better. I think you said early you think of it as the stage where people adjust to 'business as usual.' That is what it feels like, too. I am accepting invitations and returning to what was our normal life.

Magda: Having our third child moved our life into a healthier perspective, so I suppose we shouldn't feel very complacent about how we feel now, but there is a difference in how we feel.

Kevin: We can see the reality and cope with it, but if I hadn't had the other baby I'm not sure where we would have been.

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8 Guilt and/or Blame

It is my fault. It is their fault.'

Magda: There were times when I felt guilty about being on this earth. When we were going over and over the whole business, over and over again with all those clinics and agencies, I got so I felt a great big problem to the whole world. I'd apologise for being such a trouble to everyone. One day I got fed up and asked what they wanted from me. The poor guy just about fell off his chair. He blinked and mumbled. The next thing we were dismissed. I'd had it!

Cheryl: I looked for reasons to feel guilty. Was it my fault because I had to take pain-killing drugs while I was pregnant. Was it an injury from an accident—anything that I could have avoided. I blamed myself over and over again.

Mark: Well, I have to say that I blame the incompetence of the doctor. Even as we talk now I can feel my fists stiffen ready to smash him. My wife is a person who knows about birth procedure and she said not to induce the child, but she was overriden by the staff with some line . . . Well, when you're told it'll be better for the baby, you acquiesce, don't you? Later the truth came out. The doctor had left instructions that the baby's birth had to be over by a particular time because he had another engagement. That child of ours suffered this damage so that a doctor could keep a social engagement. Oh yes, I have a deep, righteous rage when I know he is to blame! Apparently, the theatre sister made a complaint to the hospital directors—that's how disgusted she was.

Bill: I didn't do anything wrong, so of course I do not feel guilty. And what's the point of blaming anyone, what will be will be.

Donald: I get the feeling that professional staff expect you to feel guilty, but we never have. However, we were fortunate because the specialist explained that the birth anomaly was ideopathic—that no one knows why it happens. So that probably saved us from guilt. And blame, how could we blame anyone. Everybody has been so tremendous throughout the whole thing. Although, I feel guilty in comparison with other people.

The most significant word in the guilty or blaming person's vocabulary is 'should'. Either they, or someone else 'should' do, or 'should' have, done something.

Anger seems evident as you watch the body language. Clenched fists and other hostile activity are common. Frequently there is an ambivalence between guilt and blame. Perhaps in a desperate effort to understand the cause of the brain damage, the parent searches for reasons and, perhaps, if none can be given this uncomfortable feeling begins causing an erosion of rationality.

Brain damage is an extremely complex condition. Medical staff would prefer to give positive reasons and explanations, but as this can seldom be done they can only report to the parent what they know. Although this is frustrating there is no other alternative until more information on the brain is known.

It is a great relief for the guilty/blaming parent to know that he or she has permission to talk about it. However, at the same time, it must be pointed out that they have to make the choice about whether they get stuck in this phase or move on. This is essential for the parent who cannot come to terms with not receiving precise diagnosis and prognosis. If in reality they will never receive clear answers to the questions, then it would be irrational for them to block themselves on this issue. They will never learn to live comfortably with themselves, the child and the condition, unless they put the guilt and blame in the past and learn to live with the reality of the here and now.

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The whole process of grief is growth. Growth and learning from the experiences. It is a process of change and what we do with it is up to us.

Summary

Living with grief is possible as is witnessed in this section. This is not to infer that there will be no more pain, but having come this far each parent has adapted to the crisis.

Tom's final comment sums up this stage best: 'The whole process of grief is growth. Growth and learning from the experiences. It is a process of change and what we do with it is up to us.'