

Why Me ? Why My Child?



**Alvin Buckwold Child
Development Program**

Introduction

Children. The center of our family life. The embodiment of our hopes and dreams. Our future. If you were to look for just one positive, binding force that cuts across political boundaries and cultural difference it is the importance of children.

When we become parents most of us have some basic expectations of what our future holds that we don't even think about. Our child will grow and develop, walk, talk, and learn in the usual ways. Eventually he or she will become independent, find a partner and have children. Nothing prepares us for the possibility that our child could have serious health issues to sort out that could put those expectations into question.

Why Me? Why My Child? is our heartfelt cry when we are facing developmental delays or disabilities for our child. We are thrown into the turmoil of having to sort out what is happening, do what is necessary, and deal with all the emotions involved.

This booklet's purpose is to help you go through this difficult process. The new problems we face will need new ways of coping to solve. Because each of us is different, what will work for you is not exactly the same as what will work for someone else. What this booklet hopes to do is to point out some of the challenges, and things that can help.

Anita Grosse, B.A., M.S.W., R.S.W.
Social Worker
Alvin Buckwold Child Development Program
Saskatoon, Saskatchewan
September 2006

Exploring Your Feelings

Emotion. That response in ourselves that produces so many different feelings in so many different ways in all of our relationships.

Many of us go through life not thinking very much about our feelings. We know that sometimes we are happy or sad, that some things make us angry and other things make us excited. We see this as ordinary life and we don't worry very much about it.

When we become parents, most of us find that our world tends to center on our children. The depth and power of our emotional responses to issues about them sometimes catches us by surprise. This is particularly true when health issues arise that threaten our children's future and well being. Our bond with our children is so great that anything that threatens our child can feel like a direct threat to ourselves and indeed the whole family. Just having to go to a place like the Alvin Buckwold Child Development Program "to have an assessment done" can feel this way.

Going through various assessment processes with a child is stressful. Expect that you may have more questions than answers for a while. First questions almost always include:

- What is wrong?
- Why did this happen?
- How do we fix it?
- What does the future hold?

As important as these questions are, the answers to them are often unclear for long periods of time. Sometimes it is just a fact that the child himself (herself) will have to show us how well he can do. The anxiety of “waiting to see” can be frustrating.

Try to balance this with the fact that the future is not really certain for any of us, adults or children even when we are perfectly healthy.

What may become clear is that our child will need extra help or therapy to do as well as possible. As parents this is often hard to face, because it also tells us that our child may have a developmental delay or disability.

This is a challenge that:

- touches every thought we ever had about being a parent and raising a child.
- affects our sense of who we are and what our lives are all about.
- sends us down a road we would not choose to travel.

As we begin this journey we sometimes feel overwhelmed by the huge amounts of information we are expected to hear, to understand and to act on. We gather up our courage to keep on going. Know that while most parents have the same kinds of feelings we don't all experience the feelings in the same way, or at the same time. Our responses are as different as we are. We find ourselves grieving.

Grieving

What is it?

Grieving is a normal, healthy response to loss. It is a complex experience involving your whole being. Your emotions, your thoughts, hopes, fears, and relationships are all affected. Your body also can react with changes to such things as your sleep pattern or your appetite.

Although grieving and loss are very closely connected, talking about “losses” can sometimes be confusing. We just aren’t used to thinking about the fact that anything that makes us or our child different from other children, produces a loss for us. Things like needing to change our normal expectations about our child’s mobility, or learning, are losses. So are the changes we must sometimes make to our lifestyle or our finances because of our child’s special needs.

The experience one person goes through can be quite different from that of someone else.

- Some of us tend to deny what’s going on. We ignore or minimize the problem, deciding things will soon be back to normal.
- Some of us feel we must “always be strong,” that showing/sharing our feelings is “weak,” that we must not “give in” to our feelings.
- Some of us get angry and stay that way for a long period of time. We randomly direct our anger at ourselves, the doctor, therapist, family, friends-even our beloved child.
- Others fall into a depression, feeling helpless, hopeless and unable to see a way to continue.

Coming to terms with such difficult feelings is hard and takes its own time. What you need to understand is that your reactions are absolutely normal and appropriate to the intense grief you are experiencing.

Understanding something about grieving - what to expect as well as our own individual response to it - is a first step that helps us recover our emotional balance. This in turn allows us to regroup, get our strength back and begin to function more smoothly again.

- 1) The first thing to understand about grief is that it is a natural response to difficult events. The society we live in hasn't done a very good job in helping any of us learn how to deal with uncomfortable, difficult feelings like anger, or fear, or frustration. None of us like such feelings and it's pretty normal to want to ignore them or get rid of them as soon as possible.
- 2) The second thing to understand is that you can't escape grieving just as you can't make your child's disorder go away. The many feelings you experience become a natural and necessary process that your mind and body need in order to deal with emotional pain. When you begin to come to terms with your pain and are willing to face it, you will find that grieving is a healing process.

Grieving is often described in terms of “phases” or “stages” that people go through following a loss. Not everybody experiences every stage in a particular order but it is best to be prepared for the strong feelings that may be encountered.

Denial

Sadness

Fear

Isolation

New vision of Life

Depression

Shame

Anger

Guilt

Denial

This is one of our most misunderstood responses. “Numbing out” after the shock of bad news is common. When we see someone “not reacting” to serious problems it is easy to assume they “don’t care.” Sometimes we think the opposite and assume the person is strong and needs no support. Neither one of these assumptions is accurate. We ourselves sometimes feel embarrassed when we realize we’ve been “going through this denial” as though it was a negative thing and we should never be there. This is far from the truth.

Denial is an important part of how we cope. Its job is to slow down the impact of serious problems in our life, giving us a chance to regroup and gather our strength and support. We show we are overwhelmed and need to slow this process down in many ways. Some of us become emotionally distant and may not be able to either share our burden with others or be there for others emotionally. Others become work-a-holics or get very busy with other activities as a way of avoiding dealing with the impact of our new situation.

Sometimes we comfort ourselves by minimizing the problem. We tell ourselves “this isn't really serious. My child will be back to normal soon.” This minimizing helps us, particularly at the beginning of our journey, by giving us back some sense of personal control. It allows us to let the full impact of a new future unfold at a speed we can manage. It only becomes a problem if we become frozen and don’t find a way to move through it.

Guilt / Shame / Isolation

As parents, our bond to our children makes us emotionally vulnerable to them. When serious health issues develop, we search everywhere for the cause, desperately needing to understand "why." In our emotional pain, and because of our great love for our children, we tend to blame ourselves first. We think, "if only I hadn't taken.... when I was pregnant", "if only I hadn't been so busy", "if only I hadn't.... " In our self-blame, our self-image also takes a beating as we wonder "is there something wrong with me to produce this result" or "is there something wrong with my partner." In a cruel twist of fate, right at this point, when we are the most vulnerable and so badly need support, such questions can make getting that support from those we love the most, more difficult. We feel isolated and alone in our grief.

Such agonizing feelings are normal. At different times, your partner and other close family will have similar feelings of their own. It may help to know that in talking and sharing some of this with your family, you will be able to help each other. Gradually you come to realize that as much as we need to understand "why," blaming yourself or anyone else, gives no answer at all. The simple truth is that for the great majority of situations, no one is to blame.

Anger / Fear

Anger is another of those uncomfortable emotions that we don't understand very well. Most of us see anger as negative, and as an emotion we should just push away or get rid of as soon as possible. But anger, like other difficult feelings, is also natural, and in fact has an important and positive function.

For most of us, having some degree of power and control in life is very important. Being able to control at least part of our life - such as what we do about a career, who our partners are, the lifestyle we choose, having children (or not) - is what tends to define us as individuals and as adults. When something or some event takes that control away we feel fear, anger, and outrage.

The biggest emotional impact we experience when serious health issues affect our child stems from this loss of power. We couldn't prevent the disability that has happened. We can't fix it ourselves. We are dependent on the medical system, not on ourselves, to make things better. We can't control the outcome. We can't make it go away.

With this comes fear. We have lost our normal sense of control of both our present life and our future. The unknown makes us fear for our child. We fear for ourselves. We are sometimes afraid we might not be able to cope.

Fear makes our search for “what is wrong” and “why did this happen” so intense that our search often continues for a long period of time.

Many of us feel huge anger at this time and we sometimes have difficulty with where to direct it.

- We can be angry with ourselves, at our partners, even our child.
- We can be angry at family and friends for not being there - for not being able to help - for not understanding - for not being able to take our pain away.
- In our drive to know and understand, we can be angry at doctors, at therapists, at the medical systems involved. The frustrations we experience in our search for solutions can also produce a deep-seated rage. Rage because no one helped us foresee this. Rage that no one solved it quickly. And in particular, rage that no one can change it.
- We can be angry at this unwanted and unforeseen change in our life.

Our sense of justice is also part of this anger. We question what we did to bring this on. We know neither we, nor our child, deserved this. We have an overwhelming sense of its unfairness.

As difficult as our anger is, it also has two important positive functions: tension release and providing the energy necessary to find solutions. The intensity of emotions produced by our child's health concerns, and the often-lifelong nature of these problems, combines to create a buildup of stress. It demands some form of release.

Anger itself serves to provide a sort of safety valve, a way to "blow off" the pressure that builds inside. In that sense, anger is good and is a protective mechanism. We often initially fear our anger, thinking of it as an uncontrolled and therefore scary, outward explosion. "Lashing out" in this way is something all of us have seen, and most of us have done. It's very human.

Some of our fear of anger goes away when we come to realize that anger produces a huge amount of energy inside us, and that *that energy can be channeled into positive action!* We can continue to search but in a much more positive way. We search out information, we search out therapies, and we search out resources. And then we "*do!*" We involve ourselves in our child's therapies, give our child endless support, and learn to do the same for ourselves and the rest of the people we love.

Depression / Sadness

Instead of turning anger outwardly, some of us turn it inwardly thinking this is somehow safer. But this is depression. Depression acts like the flip side of anger. Instead of giving us energy, depression takes it away. We can develop feelings of helplessness and hopelessness, and can feel so exhausted that we have a hard time coping with ordinary activities of daily living such as household routines or work requirements. One of the best strategies to regain our balance at such a time is to share the burden we're carrying with those closest to us. When this isn't enough, counseling or medical intervention works best.

New Vision of Life

The journey we're on is often long and difficult. Most of us go through times when we feel exhausted as we face daily challenges.

As we come to understand something about the complexities of our own feelings and accept the fact that these emotions are normal and have important, positive functions, an important change begins to happen. While we still are exhausted at times, we start to feel good even when tired. We begin to see that while our life and lifestyle have gone through forced change, it is possible to rediscover our positive self. As we see that our new life also produces happiness, our sense of having some control over our life comes back. We rediscover joy. We have a new vision of life.

Grieving as a Couple

What has become clear is the simple fact that when health problems affect our children, we as parents grieve. This can get complicated quite quickly when you consider that men and women grieve differently. Many women go through times when they want to look to their partner for mutual support, and see talking problems out as the best way to do this. Many men have been taught that they are supposed to be strong and self-reliant, and because of it find talking about feelings uncomfortable. What can make the process even more difficult is that each of you may be experiencing different parts of grieving at any one time, and may also react very differently to the same problems.

The result of this is that getting the support you need when you need it, and giving support to your partner when needed, can often be hard. It creates extra stress in your important relationships right at a time when your needs are high and your energy low.

What helps is to develop a habit of simply being aware that your partner is having a hard time too. Check in with each other about this. If this stops working or becomes too hard, it may be good to use some counseling help for a session or two, to get yourselves back on track.

Grieving as a Family

Perhaps the unkindest part of dealing with your own grieving is becoming aware that each of your children will also need to do this. Children of any age can feel sad or angry or be upset, just as you can. But how any particular child shows this can be quite unique. Children are very good at picking up on stress and tension in the family. When they do, they react. Attention-seeking behavior is very common, especially in younger children. The fact that you need to spend a lot of extra time meeting your affected child's needs can also produce some jealousy.

Children are also resilient and can be quite wonderful in what they do. They are often generous with their time and with their things. They can show great love and be very protective of their brother or sister with special needs.

All of this is normal and needs to be understood. As parents, you will be the ones to recognize that like yourself, your children need to heal. They need information appropriate to their age and level of understanding. They need support and sometimes need to talk. And as if this was not enough, as your life progresses you will discover that your child with special needs also has to cope with difficult feelings as he/she experiences "being different" from many other young people.

As overwhelming as dealing with so many important issues in your family can feel, your family life also produces the resources to solve them.

Remember that:

- The very fact that you are a family means that you as an individual are not alone in this.
- Your choice to be together is a great strength. What binds your family together is the most powerful force in the world: your love and caring for each other.
- In creating your family you also recognize that the meaning of “family life” is to go into the future together and support each other. Sometimes all you really need to do is to remind each other of that.
- Neither the problems of your situation nor the joys come all at once. You have time on your side, a lifetime in fact. Time to listen to each other. Time to help each other. Time to reflect. Time to heal.

Grieving as a Predictable Part of Life

Once we've regained some sense of balance and control in our lives, none of us want to even think about the fact that the intense feelings we've been experiencing will come back at all, let alone consider that it might actually be a predictable part of our future.

I invite you to step back for a moment and think about the ordinary experiences that every family has as their child grows. You will share in the normal sets of problems that attach to the growing pains of everyone's family life. But there will be differences and "add-ons" as well.

For example:

1) Infancy:

All children are totally dependent on their parents for food, safety, security, affection, and stimulation. This does not change with your child's disability. What does change is your child's medical picture, the assessments/treatments that may be required, and the physical, emotional and financial stresses that accompany this for the whole family.

2) Toddler/Preschooler:

This is the usual time when children are developing their own mobility and skills in verbal communication. You and your child will also be focusing your hopes and efforts in such directions.

The specifics of your child's disorder may make this difficult and frequently requires huge investments of time, energy and creativity on your part. It can be exhausting and stressful for both you and your family.

3) The School Years:

Entering and coping with the regular school system happens to all children. Again, your child may have unique challenges, which of course means that you as parent, caregiver and primary advocate, do as well.

4) The Teenage Years:

Becoming a teenager happens to all children. With this comes a whole new set of totally normal needs and goals. At the top of the list is the need for friendship, for searching out identity, for exploring and trying out degrees of independence. Your child's unique challenges will add another layer demanding unique solutions.

5) Transitions:

Becoming an adult and "moving out." There is a normal rhythm and expectation in any family for a child to grow up, move out of the home, and set up their own family. Regardless of the degree of your child's special-needs, both you and your child will eventually want this "normalcy" as part of your future. And again, the special challenges of your situation necessitate that "extra energy" and "extra creativity" to make that happen.

Outlining the complexities of family life into only five stages is the briefest of outlines of normal child rearing. The purpose here is to give you a reminder of normal parenting

process as well as a glimpse of some of the challenges that await you. It is simply important for you to understand clearly that both you and your child will together face special challenges as your child matures. There will be times when those old difficult feelings will come back. You and your child will both at times, feel anger at the unfairness of it all, or sadness in thinking about "if only..."

As your future unfolds, remember that your child will learn, will mature, and will become an adult. It is hard at times to imagine this when your child needs you so badly now. One of the wonderful things as your child matures, is to see them take their place, emotionally, as an adult able to receive and give back to you, the level of devotion you have showered on him/her. The huge effort and investment in your family that you have made can produce a depth and richness in relationship that other families may envy. Your love, care and perseverance will come back to you with interest.

What Helps?

Ways to Think

- 1) Acknowledge the simple fact that you are/have been in a hard place.
- 2) Accept that emotionally you need to be where you are.
- 3) Recognize that the stress you are/have been feeling is real. So is fatigue.
- 4) Identify the losses you have been experiencing.

Examples:

- changes in and loss of normal expectations for your child, for yourself, for your family.
- changes in financial status.
- changes in family/support relationships.

Things to Do

1) Do a little “self talk” to help yourself settle down

Remind yourself that:

- These feelings are strong and hard but they are normal.
- The best way to handle these feelings is to face them.
- This grieving is a process.
- Each person grieves at their own pace and in their own way.
- Time heals. Things will get better.

2) Reach out

- Reach out for understanding.
- Share your feelings with your partner, or friends, or supportive family members.
- Don't bottle up your feelings. Express them. Some people like to do this in writing.

3) Inform Yourself

- Learn about the condition.
- Share what you learn with people important to you and your child.

4) Strengthen important relationships

- Stay connected with your partner or support system.
- Remember that your partner may be at a different emotional point than you are.
- Think about the fact that many of your ordinary routines, commitments and expectations may need to be adjusted. It doesn't have to make your life bad. Just different.
- Talking helps.

5) Keep yourself healthy physically and emotionally

- Remember that you cannot look after your child's needs if you don't look after your own. Your own needs are important.

- Make time for yourself and for your partner, even when finding time seems impossible.
- Seek help from your doctor if you find yourself fighting depression for long periods of time.

6) Don't be afraid to use counseling services at any time, but particularly:

- When you're feeling very low and vulnerable.
- When you are having trouble sorting out what is important.
- When you need to “unload” on someone who is not emotionally involved with you.
- When you need help sorting out family issues.

If you are uncertain where to go for counseling help, talk to the social work staff at the Alvin Buckwold Child Development Program who can either help you themselves, or can help you locate other professionals if that is more appropriate.

Remember:

- Look after yourself
- Don't stop dreaming for the future
- Continue to make plans
- Let your child be a child
- Move at your own pace
- **Rediscover joy.**

Notes:

Notes:



UNIVERSITY OF
SASKATCHEWAN

Alvin Buckwold Child Development Program

Kinsmen Children's Centre
1319 Colony Street
Saskatoon, SK S7N 2Z1

Phone: (306) 655-1070

Fax: (306) 655-1449

Website:

www.saskatoonhealthregion.ca