

Emotional Baggage: Feelings that come with a rare disease diagnosis



HAVING A CHILD WITH A RARE DISEASE OFTEN BRINGS ABOUT SOME 'EMOTIONAL BAGGAGE' THAT ISN'T ALWAYS TALKED ABOUT. HOWEVER, ALLOWING YOURSELF SPACE TO FULLY FEEL THESE EMOTIONS MAY HELP YOU TO HEAL ALONG THE WAY.

GRIEF

YOU MAY GRIEVE THE LIFE THAT YOU HAD PLANNED FOR YOUR CHILD AND ALL OF THE HOPES AND DREAMS THAT YOU HAD FOR THEM. ALONG WITH THIS, REMEMBERING LIFE BEFORE THE DIAGNOSIS AND WISHING YOU COULD RETURN TO THAT LIFE ARE ALL NORMAL FEELINGS.



GUILT

YOU MAY FEEL AS IF IT IS YOUR FAULT THAT YOUR CHILD HAS A GENETIC DISORDER. "COULD I HAVE DONE SOMETHING DIFFERENTLY?" IS A COMMON QUESTION THAT YOU MIGHT WONDER.

ANXIETY

FEELING ANXIOUS, WORRIED AND AFRAID ARE SUPER NORMAL FEELINGS. AFTER ALL, THERE IS SO MUCH TO THINK ABOUT - DIET, MEDICATIONS, FORMULA, DOCTORS VISITS, MAINTAINING BLOOD LEVELS... YOU MAY FEEL AT TIMES LIKE THE WORRIES WILL NEVER END.



DEVASTATION

UPON INITIAL DIAGNOSIS, YOU MAY FEEL THAT YOUR WORLD IS FALLING APART AND THAT THINGS WILL NEVER GET BACK TO NORMAL. YOU MAY THINK "THIS IS NOT WHAT I SIGNED UP FOR."



ANGER

"IT'S NOT FAIR", "WHY MY CHILD?" "WHY ME?" ARE QUESTIONS THAT YOU MIGHT FIND YOURSELF THINKING.



ISOLATION

SEEING YOUR FRIENDS AND FAMILY WITH 'NORMAL' CHILDREN YOU MAY FEEL AT TIMES LIKE NO ONE UNDERSTANDS YOUR SITUATION.

FEAR

A FEAR OF THE FUTURE AND OF THE UNKNOWN CAN BE VERY SCARY.

HOPE

MIXED IN WITH ALL OF THE OTHER EMOTIONS, YOU WILL FEEL HOPE. THE MIX OF FEELINGS YOU'LL EXPERIENCE CAN BE OVERWHELMING, BUT THEY ARE NOT ALL GOING TO BE THERE FOREVER. REMEMBER THAT YOUR CHILD IS THE SAME PERSON TODAY THAT THEY WERE BEFORE THEIR DIAGNOSIS. AND A DIAGNOSIS IS THE PATHWAY TO KNOWLEDGE AND RESOURCES THAT WILL ALLOW YOUR CHILD TO LIVE THE MOST NORMAL LIFE POSSIBLE!

