



CHILDREN WITH DISABILITIES

Finding out that your child has a disability is one of the most shattering things that can happen to parents. It may happen at birth, after an illness or accident or you may find out something is wrong as your child develops. You may go through many of the emotions people feel after a major, sudden loss. You may feel grief at the loss of dreams for your child's future and worry about their quality of life.

There are big changes for parents and families to make that may cause stress and put pressure on relationships. It will help you and your child if you seek support early from professionals as well as from family and friends. Other parents in the same situation can be helpful too. It's also important to take time to look after yourself.

Remember that every child has different abilities. Children with a disability can have a joyful life, bring joy to others and achieve quality of life.

Quality of life

Quality of life is not about ability. It's about your child having happy times, feeling well, safe and comfortable, feeling pride in the things she can do, and that she is a loveable person. Children with a disability can lead positive, happy lives and bring joy to themselves and others.

Your feelings

When you first realise your child has a disability you may feel the grief that many people feel after a loss. This can include shock, disbelief, anger, blame, guilt, sadness, questioning why it happened to you and your child, and panic or fear that you won't be able to cope.

These feelings can (but may not) come back at times through your child's life as new losses happen; e.g. if your child can't go to the local school, make friends, or become independent. So while you can achieve some healing, it's not just one loss but a loss that may happen over and over. Take time to grieve when you need to. You don't have to manage this alone as there is help available.

How well you cope with your own feelings and your child's disability depends on lots of things:

What sense you are able to make of what has happened to your child (what you tell yourself about it). This can be affected by how well it was explained to you and what the cause was.

Your partner's reactions and how he/she copes.

The amount of support you have from family and others.

The amount of respite you have.

The relationship you build with your child.

The quality of life your child has.

The effect it has on your family life and working life.

For some people, support from their religious faith.

If you have negative feelings towards your child that won't go away it's important to get help.

Remember many parents feel this way at times.

Dealing with grief

Grief can be short-lived but more often it's a long journey of ups and downs. There may be times when it seems your grief will never really go away, but there is hope.

It's helpful to realise how far you have come. Think about when you first found out your child had a problem. How did you feel then? How were you coping? Think about how you feel and cope now. You might find you have come a long way.

If your grief does not get better over time it will affect the way you care for your child, your other children, yourself and your relationships. If this happens, seek help to work through your feelings.

Some signs that your grief is not getting better are:

If you can't seem to 'get away' from memories of your crisis.

If after time, you still cannot see anything good about your child's life.

If you can't really accept your child as he is, but still believe he will have great outcomes in ways he cannot.

If you continue to be very angry or feel very guilty.

If you are still looking for a reason it happened, after you have had all the possible information.

If you can't see any of the problems but think of it all as a blessing.

If you still have any of these feelings after a year or so, it's worth talking it over with someone.

Your needs and rights

This is your child and you have the right to say what you want for your child and to be heard. You have the right:

To look for a cure or treatment if you want to, even if your doctor says there is nothing that can be done. If your doctor does not support you, then maybe you need to try another doctor. If you feel the need to keep on looking when you've had the same news many times, you may need help to move on so that you can best care for your child.

An explanation of what has happened and why, as often as you need to hear it.

Information about your child's condition and how it will be managed, and to feel you can have some control of this.

Encouragement.

Respect.

For you and your child to be treated with dignity.

Privacy.

A break from caring for your child.

Your child's needs and rights

Your child has the right to:

Information about what has happened.

Know the words about his disability.

Information about his day to day care and treatment.

Ask questions.

Have as much say as possible over what happens to his body.

Be treated with respect.

The chance to achieve as much as he can.

Be valued as a person.

The chance to have friends.

Help to deal with being seen as different by other people.

Relationships in your family

Having a child with a disability can put stress on family relationships. It's important to deal with this for your child's sake as well as your own. It's easy to be overwhelmed and spend all your time and energy on your child with the disability and not others. It may help to:

Share your feelings with your partner and listen to his/hers.

Share the daily tasks – this says 'we're both in this together'.

Make times to have with your partner – this may be hard to do but is very important.

Remember your other children – they have as much right to your love and attention as your child with the disability. Spend time with them so they won't feel ignored or unhappy.

Grandparents

The support of grandparents can be great for you and your other children. There can be special challenges when the grandchild has a disability.

Grandparents feel pain for their own child as well as for their grandchild and may worry about the future.

Some may not want to accept that the child has a disability and may act as if it has not happened to avoid the pain.

Share your feelings and grief so you can help each other.

Grandparents are suffering from the loss at the same time as the parents, and may not be able to give parents the support they need.

Some grandparents may blame one of the parents.

They may feel they have done their child rearing, and want to live their own lives, but now feel obliged to help.

Make sure grandparents know about the disability and the treatment available.

Respect grandparents' feelings about what they can do to help.

Grandparents from some cultures may find it harder to accept disability. It might help to get support from a community leader.

Coping with prejudice

People who have a disability are at greater risk of being teased, bullied or ill-treated. You can help your child to deal with this.

Ask what practices childcare centres, preschools or schools have to deal with discrimination and bullying before you enrol your child.

Tell your child about her condition so she can answer questions about it. You might ask the teacher for the chance to tell the class about your child and answer any questions.

Help your child to find children to play with who can do the same sorts of things she can (even if she is in a mainstream school) so she can have friendships on an equal basis.

Give your child some ways to respond to teasing such as holding her head up and ignoring it, pretending there is a magic screen around her so the words can't touch her, staying near a group. You could practise this with her.

Let your child know that if she is being bullied it's important to tell an adult.

Seek help if your child is being bullied.

What parents can do

Take care of your health and wellbeing. Make sure you get breaks when you can – caring for a child with a disability can be very demanding. Accept offers of help.

Think of yourself as a partner with professionals. Ask questions e.g. what you can do to help; what other help there might be for you and your child.

Try to focus on the good things about your child – what he can do, rather than what he can't.

Try to let go of worries about the future and think about the day to day small successes.

Value your own strengths for coping, such as a sense of humour.

Make the effort to keep in touch with supportive family members and friends.

Try to find the balance between protecting your child and letting him be as independent as he can. All children need the chance to be their best.

Have faith to let your child experience some risks.

Teach your child about caring for himself

It is often easier and quicker for parents to do things for children with a disability, rather than teach them to do things. Being able to do even small things is one way children learn to feel capable and good about themselves. Children with a disability have fewer things they can do, so it's worth the effort and time to teach them to do what they can.

Some things to think about are:

Show your child how to do things. You may have to show them over and over. Talk about what you are doing as you do it e.g. dressing her.

Break down tasks into small parts so your child feels capable even before she can do the whole thing. Help her learn one step at a time e.g. pulling up her pants as the first step she can be proud of towards toilet training.

Try not to criticise mistakes. Focus on the bits your child gets right. Just try again when things go wrong.

Don't expect too much. If your child is getting upset and frustrated, maybe you expect too much. On the other hand give her the chance to try things without rushing in to help too soon.

Find things your child can do to help – even if she just holds a bowl while you peel the vegetables. Let her see that you value her help. Everyone feels better if they can do things to help.

For children with a disability an occupational therapist can often help with tasks that seem too hard to manage.

Have faith in your child – and show her that you have faith in her.

Children and young people with disabilities go on learning new basic skills well after other children can do the same things. Even as young adults, they go on learning new basic skills.

Teach your child about safety

Many parents try to look after their children so well they never leave them in an unsafe situation. It's important to protect children but you can't be there all the time.

Children with a disability may not be as able as others to keep safe. As they get older, it's important to teach them how to keep safe as far as they are able to. Even learning a few rules will help them and help you to worry less. Teach what to do to keep safe rather than through fear of what might happen to them. Give lots of encouragement for small successes.

Teach your child according to what is suitable for his age and development, what he can understand, and is able to do.

Teach:

How to keep safe at home e.g. around fire, water hazards, electricity, pets, answering the phone or knocks at the door. You might have a rule about taking medicines so that he can only take it if you (or a named person) give it to him.

To stay within safe boundaries e.g. within your home fence or other areas, how to behave while you are shopping or visiting other places.

How to stay safe when using roads, footpaths or public transport.

How to act in relation to strangers.

About unsafe touching and other forms of verbal and physical abuse, and what to do if it happens.

His home address and phone number (or your mobile phone number) so he knows how to contact you or can tell others – or make sure this information is written down and carried with him if needed.

How to use the home phone or his mobile phone (if you can provide one) to call you or another family member or trusted friend, and how to call an emergency number for help.

Child care and school

Many children with disabilities now go to mainstream child care centres, kindergartens and schools. Wherever they go, it's a large part of their lives and important it works well for them. Speak to staff well before your child is ready to start. Make sure they know your child's needs and abilities and can put supports in place.

Some issues can be:

Not having structures in place, e.g. ramps for wheelchairs, suitable desks or computers.

Teachers not understanding the condition.

Missing school and losing touch with friends.

Having to spend a lot of 'free' time catching up with work.

Bullying and teasing.

What parents can do

Check out the service or school first and make sure it's right for your child. Take your child with you when you visit.

Ask about extra resources there might be from education, health or other agencies, e.g. support staff, computers, ramps.

Help your child learn to manage her own clothes and needs as far as possible so she can feel and be independent.

Find out what school activities your child can take part in, e.g. drama, music and outings. Being part of things can make children feel much happier and more confident.

Let the teachers know if tiredness or pain or coordination problems make it hard for her to do some tasks. All her teachers need to know about this, not just classroom teachers. Support from teachers is very important.

Keep up contact with teachers so any problems can be sorted out early and you can both share successes too.

It may help to have a health professional come to the school and talk to the children and staff about your child's health problem and how they can help.

Try to arrange health/medical appointments during school holidays so your child misses as little school as possible.

Friends are very important for your child so encourage friendships where you can and make it easy for your child's friends to visit your home.

Growing up

As your child grows up there will be new challenges to face. Some parents try to avoid these by keeping their children young and avoiding new situations. You can help prepare for the process of growing up and 'letting go'.

Teach your child about sexuality and keeping safe. Some young people with disabilities may need help to cope with sexual feelings and how to express them in an acceptable way. They may also be at more risk of abuse. Teach them to say 'No'.

Involve them in deciding about their own care as much as they can.

Give your child practice in doing things themselves where possible, e.g. weekends in respite care, trips away, belonging to groups.

Growing up can present emotional problems for young people, as they may want to be part of the group but find it hard, or have many limits on what they can do. They will realise more and more the differences between them and others.

Find out the options for future care and try to arrange for future living plans while you are still able to help your child through the change.

If you have spent a lot of years caring for your child, think about where you can spend that energy from now on. There may be some grieving about these changes, as well as positive new directions.

Most services encourage family contact either by day or with overnight stays. Apart from not losing contact, it allows you to help staff continue your child's care as it was at home.

Services that have supported your child may value some voluntary help. You may want the chance to get back to work, or you may take up a hobby you didn't have time for before.

Reminders

Having a child with a disability can be stressful and demanding.

Children with a disability can have happy, enjoyable lives. Remember every child is different – focus on the positive things about your child.

Think of yourself as a partner with professionals and work with them – remember you know your child best.

Teach your child to look after himself and keep safe, as far as he is able.

You have the right to expect the same standard of health care and support for your child with a disability as for any other child.

It can be helpful to find a support group of parents with similar experiences. Keep up your contact with supportive family and friends.

Take time to do things for yourself. Looking after yourself and your relationships is important for you and your child.