



"Massive Minds, Huge Hearts, Guided by God"

Children with a Disability

Finding out your child has a disability can happen at birth, after an illness or accident or you may find out something is wrong as your child develops. 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 can cause stress and put pressure on relationships. It will help you and your child if you seek support early from professionals, family and friends or other parents in the same situation.

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 they can do, and that they are 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. For example, 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 can make of what's happened to your child, and 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.

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Every child has different abilities. Children with a disability can have a joyful life, bring joy to others and achieve quality of life.
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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 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
- after time, you still cannot see anything good about your child's life
- you can't really accept your child as they are, but still believe they will have great outcomes in ways they cannot
- you continue to be very angry or feel very guilty
- you are still looking for a reason it happened, after you have had all the possible information
- you can't see any of the challenges 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 them and to be heard. You have the right to:

- 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 and privacy
- be treated with dignity - both you and your child

- a break from caring for your child
- to seek opinions from a range of professionals.

Your child's needs and rights

Your child has the right to:

- information about what has happened
- know the words about their disability
- information about their day to day care and treatment
- ask questions
- have as much say as possible over what happens to them
- be treated with respect
- the chance to achieve as much as they can
- be valued as a person
- the chance to have friends
- help to deal with being seen as different by other people.

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.

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 a disability and not others. It may help to:

- share your feelings with your partner and listen to theirs
- share the daily tasks - this says 'we're both in this together'
- make time to spend 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 a disability. Spend time with them so they won't feel ignored or unhappy. Don't put too much responsibility on them.

Grandparents

The support of grandparents can be great for you and your other children. There can be special challenges when a 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 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.
- Make sure grandparents know about the disability and the treatment available.
- Respect grandparents' feelings about what they can do to help. They may feel they have done their child rearing and want to have time to themselves.
- Grandparents from some cultures may find it harder to accept disability. It might help to get support from a community leader.

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, for example what can you do to help, what other help is there for you and your child?
- Try to focus on what your child can do, rather than what they can't.
- Try to let go of worries about the future and think about the everyday 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.
- Let your child experience things for themselves, including taking some risks.
- Teach your child about caring for themselves.

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

Helping children to learn

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

You could:

- show them how to do things — you may have to do this over and over. Talk about what you are doing as you do it. For example, dressing them

- break down tasks into small parts so your child feels capable even before they can do the whole thing. For example, pulling up pants as the first step to be proud of when toilet training
- try not to criticise. Focus on the bits they get right. Try again when things go wrong
- don't expect too much - your child may get upset and frustrated. On the other hand, give them the chance to try things without rushing in to help too soon
- find things your child can do to help — even if they just hold a bowl while you peel the vegetables. Let them see that you value the help. Everyone feels better if they can do things to help
- contact an occupational therapist — they can often help with tasks that seem too hard for children to manage
- show your child you have faith in them.

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Children and young people with disabilities can go on learning new basic skills well after other children have learned these things.

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Learning 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. As they get older, help children learn safety rules as far as they are able. Try not to frighten them about what might happen. Give lots of encouragement for small successes.

Help them to learn according to what is suitable for their age and development, what they can understand and are able to do. Teach:

- how to keep safe at home. For example, around fire, water, electricity, pets, answering the phone or knocks at the door. You might have a rule about taking medicines so that they can only take it if you (or a named person) give it to them
- to stay within safe boundaries. For example, 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
- their home address, phone number or your mobile phone number so they know how to contact you or tell others. Make sure these are written down and carried with your child if needed
- how to use the home phone or their mobile phone to call you or another trusted person, and how to call an emergency number for help.

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

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Child care and school

Many children with disabilities go to mainstream childcare centres, preschools 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 support in place. Some issues can be:

- the need for wheelchair ramps, suitable desks or computers
- the need for additional learning support staff and input from services such as speech or occupational therapy
- teachers understanding the condition, and what your child is able to do or needs help with
- your child missing school and losing touch with friends due to attending appointments or being unwell
- bullying and teasing.

How parents can help

- 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 from education, health or other agencies. For example, support staff, computers, ramps.
- Help your child learn to manage their own clothes and needs as far as possible so they can feel and be independent.
- Find out what school activities your child can take part in. For example, drama, music and outings. Being part of things can make children feel much happier and more confident.
- Let the teachers know if tiredness, pain or coordination problems make it hard for your child to do some tasks. All your child's teachers need to know about this, not just classroom teachers. Support from teachers is very important.
- It may help to have a health professional come to the school and talk to the children and staff about your child and how they can help.
- Try to arrange 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. Make it easy for your child's friends to visit your home.

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

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

- Involve your child in deciding about their own care as much as they can.
- Let them practise being more independent. For example, 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. If you are worried about your child's emotional health talk with your doctor or health professional.
- Be aware that some young people may need help to cope with sexual feelings and how to express them in an acceptable way. They may need support to deal with friendships and relationships.
- As your child gets older, find out about options for their future care. Transitions like this can take some time to arrange, and it's good if your child has your support to adapt to changes.

You can get further advice and information from:

- School, Mrs W Jennings SENDCo
- Family Carers - <https://suffolkfamilycarers.org/events/>
- Suffolk Young Carers - <https://suffolkfamilycarers.org/young-carers/>
- Suffolk Parent Carer Forum - <https://suffolkpcf.co.uk/>
- <https://suffolksendiass.co.uk/>
- Activities Unlimited - <https://www.access-unlimited.co.uk/activitiesunlimited/>
- TOPCATS Support for young people with additional needs - <https://infolink.suffolk.gov.uk/kb5/suffolk/infolink/service.page?id=K0L88NFstcs>
- Disability Living Allowance - Telephone: 0800 121 4600.
- Cinema (CEA) Card (available if you receive Disability Living Allowance) - <https://www.ceacard.co.uk/>
- <https://www.suffolk.gov.uk/children-families-and-learning/wellbeing-for-education-return/family-wellbeing/>
- <https://www.justonenorfolk.nhs.uk/childhood-development-additional-needs/developmental-stages>
- <https://www.justonenorfolk.nhs.uk/childhood-development-additional-needs/additional-needs>