



Supporting siblings

Some ways in which families can support the brothers and sisters of a child with Down syndrome.

1. Initiate and maintain a dialogue about Down syndrome, involve siblings and keep them informed.

It generally helps to have open discussion of Down syndrome and disability within the family – in conjunction with discussion of the ways in which we are all similar and diverse. Explain the disability and make it part of your family dialogue. It is important to keep information and language simple for young children. Siblings will be asked questions and may have to deal with misleading and sometimes unpleasant or hurtful information about their brother's or sister's disability, so provide them with the skills and information they need to handle this confidently. Involve them appropriately in matters arising as a result of their sibling having Down syndrome.

See also: *Talking to siblings about Down syndrome*
What to say to children about Down syndrome

2. Encourage open communication including the expression of negative feelings. Listen!

Studies have shown that resilience in families relates to being able to communicate, including about difficult issues. All siblings will experience negative feelings about their brother or sister at some point: frustration, anger, resentment, jealousy, shame, embarrassment. This is not unique to sibling relationships which involve an individual with Down syndrome. Siblings must be able to express and have validated their feelings and concerns surrounding their sibling(s), both positive and negative, without fear of reprisal. Given an appropriate context for the discussion, make sure you listen to siblings real concerns (and distinguish these from regular sibling gripes), help children express their feelings, validate their feelings and experiences and give them permission to express negative feelings (eg "It must be hard sometimes having a sister with Down syndrome", "I can see that you are struggling with your brother at the moment", "Let's talk about what will make things better").

Siblings are likely, at some point, to experience the same feelings of

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grief or guilt that many parents experience when they learn that their baby has Down syndrome, and may also share concerns that parents have regarding health, safety, emotional wellbeing and future scenarios.

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3. Ensure, as far as possible that the sibling with Down syndrome does not receive special treatment.

It is important to have the same fundamental expectations of behaviour, cooperation, family dynamics and responsibilities and rights for *all* family members. Having Down syndrome should not exempt a family member from the norms that apply to everyone else. Household responsibilities and chores can be shared by everyone – responsibilities should correspond to each individual's capacities and maturity.

And the same behaviour norms should apply to everyone – having Down syndrome does not mean you can behave badly, although it may mean more effort to teach the right behaviour.

4. Acknowledge where extra time is spent because of the disability. Allocate time or attention to all siblings.

Siblings sometimes feel that the child with Down syndrome receives more time and attention from parents, and others, than do other children in the family. Where this is the case, extra time spent in appointments, therapies, school work, extra practice of life skills etc should be acknowledged – it may be useful to focus on the condition rather than the person as requiring extra attention. It may also help to refer to meeting everyone's needs within the family rather than referring to equality and fairness. Remind siblings that, although it may sometimes seem that their sister or brother with Down syndrome gets more attention than they do – and she/he may need extra help and take more time to learn things – that you love them all equally, and they are all equally important to you. If possible try to ensure that all siblings get some time alone with parents.

You may find that you need occasionally to gently remind friends and relatives (and childcare staff, teachers etc) not to pay less attention to siblings than to the family member with Down syndrome.

5. Acknowledge and celebrate everyone's achievements and talents.

There can be a tendency to celebrate each small progress step of the family member with Down syndrome and take for granted those of everyone else.

It is important to ensure that the accomplishments of ALL family members are celebrated, as equally important. Siblings need to feel

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special and valued too. Acknowledge everyone's strengths and weaknesses, ways in which you are different and things you hold in common.

6. Ensure you don't pressure siblings to achieve or to be good

Some studies have indicated a tendency for parents to expect greater achievement or a higher standard of behaviour in siblings of children with a disability. Beware of giving the impression that siblings need to compensate in some way for each other's differences as this is likely to produce self esteem issues and conflict within the family.

7. Avoid putting excess responsibility on siblings.

Families need to guard against over-stressing caring responsibilities for siblings. It is not fair on either sibling and is likely to have a negative effect on their relationship. Emphasising the need for mutual support in the family to meet everyone's needs, and assigning roles and responsibilities to everyone which align with the capacities of each individual, may help maintain balance in this regard.

It may also be prudent to avoid excessive use of age and maturity related terminology. Terms such as 'little brother' and 'big sister' often have ranked behaviour and responsibility connotations, and can lead to frustration in families where there is likely to be a cross over in the level of development and maturity of siblings at some stage.

As in all families, as siblings grow so does their need for their own space and for time for themselves or with friends, away from the family.

8. Provide access to age peers who have a sibling with a disability.

Many siblings will benefit greatly from meeting other people their age who also have a brother or sister with a disability. Sibling peer groups are available in many areas and web-based networks allow siblings to connect, chat and stay in touch. Contact Family Support at Down Syndrome Victoria to find out more about these opportunities or use the links on the *DSV Siblings resource list*.

References

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