Children's Liver Disease Foundation
fighting childhood liver disease

Bereavement

A Guide

Information on coping with the loss of a child

This information has primarily been written for:

- parents/carers of a child with liver disease who has recently died

Others who may also find this information useful:

- family and friends of a child with liver disease who has recently died

It provides information on:

- practical ways to deal with grief
- advice regarding dealing with siblings
- advice regarding dealing with grandparents
- other sources of information

Coping with grief

There is no 'right' way to grieve and as a parent you will react in your own way, you'll feel different emotions at different times and will find your needs will change throughout the grieving process. When your child has died you need to focus on what you need to do to get through every day and night.

It can feel as though your grief is all consuming and always will be but at other times it may feel more manageable. It will take time for you to feel a manageable amount of grief most of the time but this will happen.

Different members of the family can grieve differently and can have different emotions and needs at different times to you. You might find it hard to understand how another family member is feeling even though you are both grieving. Communication can be really important to help each other understand what each of you need, even if it's time and space.

Let others know what help and support you need at this time. Often people want to help but don't know how.

Look for additional support if you need it. CLDF does not offer specific bereavement services but can signpost you to bereavement services across the country. There are many charities and helplines offering a wide range of support from a friendly ear on the phone to counselling sessions. Getting extra support can help you to normalise feelings, allow you to share your experiences and talk with others outside the family.

Even if you don't feel like this is helpful immediately after the death of your child you may find it beneficial further along the grieving process.

After your child has died there are many different things that need sorting out. There is no right timetable to do this or a right way to approach it. Remember that you should do what feels right to you when it feels like the right time.

Seeking peace, comfort and hope: Religious and spiritual care

Losing a child to a liver disease is an understandably enormously sad time and can be a time when we need comfort, seek to make sense of our loss and find hope and meaning. It may be helpful to you in your bereavement to have some spiritual and/or religious support.

Almost all hospitals will have a chaplaincy team (representing the most common religious communities in your area), to offer you a listening ear, a prayer or a blessing.

Some will have activities and rituals which your family can take part in.

These can be a great comfort and allow you to find some peace, hope and belonging in the midst of difficult times. If a religious leader has led your child's funeral, they would also be able to offer on-going support. Many chaplaincy teams will also offer memorial services and events during the year.

All of these people will have the wisdom to offer you support regardless of whether you have a formal religious faith or not, as we are all spiritual beings in need of human care in times of sadness.

Advice for parents regarding how to deal with siblings and grandparents

Siblings

Children of different ages grieve very differently. There are four main concepts regarding death which children learn to understand:

- that all living things must die
- that death is irreversible
- once a person dies their body can no longer function e.g. walking, seeing, eating
- that there are physical reasons someone dies

Children will develop understanding of these over time. Most children will learn these concepts between the ages of five to seven whilst older children are more likely to understand them.

Babies and very young children don't understand death but will sense the emotions of those around them. They may become more clingy than usual. Keeping your usual routine can be helpful for them.

Children of pre-school age often know of death but may not understand that death is permanent and irreversible. When talking to children about death using concrete language is important instead of euphemisms such as ‘passed away’ or ‘gone to sleep’.

Children deal with their feelings differently at this age; they may appear unconcerned at times or they can seem unfeeling as they get on with their day/play. Emotions are often expressed through play and there may be changes to behaviour, e.g. regression to behaviour of a younger child, clinginess or angry outbursts.

School aged children are more likely to understand that death is final but they still benefit from clear and concrete language. They may have questions about death and they may not understand that everyone dies or why they die. They can sometimes believe that they may have caused the death of their sibling, e.g. 'my sister died because I told her I hated her'.

They can need explanation and reassurance that it was not their fault. They may start to attribute death as happening to others and ask parents when they are going to die, being watchful or staying close by a parent, etc. If a child is anxious about when others may die it can help to reassure them that not everyone who is ill dies and help them to manage their anxiety which may include relaxation methods.

Children at this age may struggle to concentrate in school, may have emotional outbursts or may report physical symptoms such as tummy aches/headaches.

Teenagers process death in the same way as adults. They may start to think about the meaning of life and have unanswerable questions. They are more likely to engage in risky behaviours and they may experience guilt about being alive whilst their sibling has died. The death of a sibling can trigger anger and it can sometimes cause teenagers to become withdrawn.

Useful ways of helping at this stage can include:

- encouraging them to talk/express feelings in a journal/ drawing/creative outlets
- modelling your own coping strategies, e.g. relaxation or exercise

Don’t be worried about crying in front of your children, it can help to let them know why you’re upset and shows them it’s OK to feel sad.

Give siblings plenty of reassurance that you love them and you are still there to care for them.

Encourage questions. You may not have all of the answers but it can be good to discuss things.

Grandparents

When a child dies their grandparent is not only grieving for their grandchild but also for their child who is experiencing pain. It can be difficult for grandparents to know what to do or how to help. It can be helpful if parents acknowledge the pain and grief of the grandparents and let them know how they can be helpful.

Grandparents can:

- ask parents and families what they need without telling them what they 'should' be doing and how they 'should' be feeling.
- not avoid talking about their lost child if they want to talk about them.
- stay away from saying things like 'I could never be as strong as you', 'I couldn't cope with what you are going through' – parents often say this can be frustrating as they have no choice but to cope and be strong.

Remember to take one day at a time. If you feel unable to cope, you are not alone. You can talk to your family and friends, you can contact CLDF's support team and you can contact the services listed here.

We are not automatically informed when a child dies so if you can please let us know. If you feel you can't inform us, you can ask your hospital, a friend or relative to do so on your behalf. A member of the families' team will then get in touch with you, if you would like us to.

CLDF's support does not end when a child dies. We understand that the family starts a new, individual journey. You can contact the support team at any time. There are a number of different services available for those who have lost a child. These include:

CLDF anniversary cards

After informing the CLDF team of your child's death we will send you an anniversary card every year. Many parents find this comforting, however if you don't want to receive an anniversary card or find that after a number of years you would no longer like to receive it then just let us know.

CLDF Memory Book

CLDF has a Memory Book in which the name, date of birth and date of death of your child is written by a calligrapher. Children and adults of any age can be included in the book, whether or not you have had contact with CLDF before their death. You can come and visit the CLDF office and see the book at any time. It's also displayed at our national conference and family weekend held every two years.

Having your child's name recorded in CLDF's Memory Book can be a wonderful way to commemorate the life of your child. If you would like to do this please contact the support team using the contact details at the back of the leaflet.

CLDF memorial service

The National Memorial Arboretum is home to a CLDF tree in memory of the lives of children and young people lost to childhood liver disease. We hold a memorial service here every two years at which we welcome the families and friends of those who have died to join us for a non-denominational service.

Other services

There are many bereavement services which can support you following the death of your child. A number of national services are listed on the next page. To find out about more services local to you please contact CLDF's families' team.

The Compassionate Friends (TCF) www.tcf.org.uk

TCF offers online support, a telephone helpline and local support groups.

Child Bereavement UK www.childbereavementuk.org

Child Bereavement UK supports families when a baby or child of any age dies or is dying, or when a child is facing bereavement.

Cruse Bereavement Care www.cruse.org.uk

Cruse offers support, advice and information to children, young people and adults when someone dies and works to enhance society's care of bereaved people. Cruse offers face-to-face, telephone, email and website support.

CLDF produces a wide variety of information resources for children and young people up to the age of 25 with liver disease, their families and the healthcare professionals who look after them. This information can be downloaded or ordered from CLDF's website www.childliverdisease.org. For further enquiries regarding CLDF's information please contact the Health and Research Information Manager by email at hrim@childliverdisease.org or call **0121 212 6029**.

Thanks

This leaflet has been written, edited and reviewed with the help of staff at each of the specialist paediatric liver centres: Birmingham Children's Hospital, King's College Hospital and Leeds Children's Hospital. Thank you to all of the staff involved who have made the production of this leaflet possible.

Feedback and Information Sources

Information within this leaflet has been produced with input from the three specialist paediatric liver centres in the UK. To provide feedback on this leaflet, for more information on the content of this leaflet including references and how it was developed contact Children's Liver Disease Foundation: info@childliverdisease.org

This leaflet was reviewed in March 2018. It is due to be reviewed by March 2021.

What is Children's Liver Disease Foundation (CLDF)?

CLDF is the UK's leading organisation dedicated to fighting all childhood liver diseases.

CLDF provides information and support services to young people up to the age of 25 with liver conditions and their families, funds vital research into childhood liver disease and is a voice for everyone affected.

Would you like to help us support the fight against childhood liver disease?

All of CLDF's work is funded entirely through voluntary donations and fundraising. Please help us to continue to support young people, families and adults diagnosed in childhood now and in the future. To find out more about fundraising and how you can join the fight against childhood liver disease you can visit: www.childliverdisease.org/get-involved. Alternatively, you can contact the fundraising team by email **fundraising@childliverdisease.org or call 0121 212 6022.**

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0121 212 3839 info@childliverdisease.org
Main site: childliverdisease.org
Young people's site: cldf-focus.org

Registered Charity Number: 1067331
Charity registered in Scotland: SC044387

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