



Understanding Chromosome & Gene Disorders

Bereavement and loss



rarechromo.org

Bereavement and loss

I have never experienced the loss of a child and I can't imagine what it must be like. I have experienced the loss of both of my parents and that was a very difficult experience to go through.

Loss isn't necessarily about someone dying, it can mean lots of different things.....When my son was diagnosed with a rare chromosome disorder at the age of one, I was devastated, it felt like I had suffered the loss of my little boy that day and all that I had hoped for his future.

COUNSELLING

Having a child with a chromosome or gene disorder or any disability can put a huge strain on your relationships, not only with your child - but with your spouse or partner. Losing that child increases that strain, so it is very important to talk to each other as much as possible and work on supporting each other. Having a supportive partner than can help you with coping strategies is the best support. Try not to bottle up your feelings, if necessary get some outside help from other parents that have suffered loss, or a bereavement counsellor or organisation.....

SUPPORT FOR PARENTS AND CHILDREN

◆ **ARC (Antenatal Results and Choices)**

<https://www.arc-uk.org/for-parents/arc-forum>

Helpline: 0845 077 2290 or 0207 713 7486 via mobile

ARC forum for bereaved parents. The ARC forum is only for people who have lost a baby following a prenatal diagnosis. It is password-protected and moderated by ARC staff. It provides a private, supportive space where bereaved parents can share feelings, experiences, coping strategies and hopes for the future. You must be registered with ARC to be signed up to the forum. It is free to residents of the UK

◆ **Aching Arms** <https://achingarms.co.uk/>

07464508994 (befriending service)

Email: support@achingarms.co.uk

Aching Arms supports parents through the devastating experience of pregnancy and baby loss. They offer a befriending service to help you to feel less alone at this time.

“ I have my Christian faith, which sadly my partner does not share. I know it may not be appropriate for many of our families - although ANY kind of faith should be of help. ”

◆ **The Miscarriage Association**

[https://](https://www.miscarriageassociation.org.uk/)

www.miscarriageassociation.org.uk/

01924 200799 (Mon-Fri 9.00am-4.00pm)

email: info@miscarriageassociation.org.uk

For anyone affected by miscarriage, molar pregnancy or ectopic pregnancy.

◆ **SANDS (Stillbirth and Neonatal Death Society)**

<https://www.sands.org.uk/>

Sands National Helpline: 0808 164 3332

email: helpline@sands.org.uk

The Helpline is for anyone who has been affected by the death of a baby and wants to talk to someone about their experience. The Helpline team are there to listen and give support, and can advise you about finding local help, whether from a Sands group or other counselling services, or information about other relevant support organisations.

◆ **At a Loss** <https://www.ataloss.org/>

A one stop shop website for finding appropriate bereavement support

◆ **Care for the family**

<https://www.careforthefamily.org.uk/family-life/bereavement-support>

A Christian faith charity for families offering support and also bereavement support days and weekends.

◆ **Child Bereavement UK** <https://www.childbereavementuk.org/>

Unit B Knives Beech Way, Knives Beech Industrial Estate,

Loudwater, High Wycombe, Bucks HP10 9QY

Helpline 0800 02 888 40

Email: support@childbereavementuk.org

⇒ **Cheshire**

Child Bereavement UK, 2nd floor Ashley House, Ashley Way West,

Widnes WA8 7RP

01928 577 164 Email: cheshiresupport@childbereavementuk.org

⇒ **Cumbria**

Child Bereavement UK, Family Support Service, The Bridge, 71 Wordsworth Street, Penrith, Cumbria CA11 7QY

01539 628 311 Email: cumbriasupport@childbereavementuk.org

⇒ **Glasgow**

Address: Child Bereavement UK, First Floor, 16 Fitzroy Place,

Glasgow G3 7RW

01413 529 995 Email: glasgowsupport@childbereavementuk.org

⇒ **Leeds**

Child Bereavement UK, Brooklands Court Business Centre, Tunstall Road,

Leeds LS11 5HL

01133 503598 Email: leedssupport@childbereavementuk.org

⇒ **East London**

Child Bereavement UK, Stratford Advice Arcade, 107-109 The Grove, London E15 1HP

020 8519 7025 Email: newhamsupport@childbereavementuk.org

⇒ **West London**

Child Bereavement UK, Beethoven Centre, 174k Third Avenue, London W10 4JL

020 8960 9476 Email: westlondonsupport@childbereavementuk.org

⇒ **Milton Keynes**

Child Bereavement UK, Sapphire House, Opal Court, Fox Milne, Eastlake Park, Milton Keynes MK15 0DF
01908 550 895

Email: mksupport@childbereavementuk.org

Child Bereavement UK helps children, parents and families to rebuild their lives when a child grieves or when a child dies. They support children and young people up to the age of 25 who are facing bereavement, and anyone affected by the death of a child of any age. They provide confidential support, information and guidance to families and professionals. Their Helpline team is available to take calls and respond to emails and Live Chat via their website..... <https://www.childbereavementuk.org/> 9am-5pm Monday-Friday.

◆ **Childhood Bereavement Network**

<http://www.childhoodbereavementnetwork.org.uk/>

National Children's Bureau, 23 Mentmore Terrace, London E8 3PN
020 7843 6309

Email: cbn@ncb.org.uk

Twitter: @CBNtweets

The Childhood Bereavement Network (CBN) is the hub for those working with bereaved children, young people and their families across the UK.

◆ **Care for the family**

Weblink: [Bereavement support](#)

Tovey House, Cleppa Park, Newport, NP10 8BA

029 2081 0800 open Monday 10:00 to 17:00, Tuesday – Thursday 9:00 to 17:00, Friday – 9:00 to 16:30

Email: mail@cff.org.uk

Information and resources for bereaved families.

◆ **Child death helpline** <https://www.childdeathhelpline.org.uk/>

Their confidential helpline is open every day of the year.

Freephone 0800 282 986 or 0808 800 6019 if calling from a mobile.

Monday to Friday 10am to 1pm Tuesdays 1pm to 4pm Wednesdays 1pm to 4pm Every evening 7pm to 10pm

Calls are heard in confidence and the helpline is staffed by volunteer parents who have experienced the death of their own child. The helpline can provide the opportunity for you to talk to someone sympathetic to your situation.

◆ **The Compassionate Friends** <https://www.tcf.org.uk/>

0345 123 2304 helpline

Northern Ireland helpline 0288 77 88 016

Email: helpline@tcf.org.uk

The Compassionate Friends (TCF) is a charitable organisation of bereaved parents, siblings and grandparents dedicated to the support and care of other similarly bereaved family members who have suffered the death of a

child or children of any age and from any cause. The helpline is always answered by a bereaved parent who is there to listen when you need someone to talk to. They can also put you in touch with your nearest Local Contact in the United Kingdom and provide you with information about our services. The Helpline also offers support and information to those supporting bereaved families. It is open every day of the year - 10am to 4.00pm / 6.30pm - 10.30pm (GMT). A faster response will normally result from a telephone call than via email.

“ Time can be a great healer, in that it takes some of the initial pain away, but love and care is more healing. Don't assume that you will upset me by talking about my child, I need to talk about my child, that is part of my healing process. ”

◆ **Epilepsy Bereaved** <https://sudep.org/>

If you have been bereaved by an epilepsy-related death call.....

⇒ **England** 01235 772852

Email: support@sudep.org

⇒ **Wales** contact line – 01656 766418

⇒ **SUDEP Action Scotland** 0131 516 7987



◆ **BLISS** <https://www.bliss.org.uk/>

Freephone Helpline: 0500 618140

Email: hello@bliss.org.uk

Support for parents of babies in Special or Intensive Care Units and for bereaved parents. 020 7378 1122.

◆ **The Good Grief Trust**

<https://www.thegoodgrieftrust.org/i-have-lost-a/child/>

Email: hello@thegoodgrieftrust.org

Facebook <https://www.facebook.com/thegoodgrieftrust/>

Run by the bereaved for the bereaved, the good grief trust offers a comprehensive online bereavement support website, to provide support both for the bereaved, whether you have lost a partner, child, parent, grandparent, sibling or friend and for the health professionals who support them.



Those we love don't go away,
They walk beside us every day,
Unseen, unheard, but always near,
Still loved, still missed and very dear.

~ Author unknown

◆ **Lullaby Trust**

<https://www.lullabytrust.org.uk/bereavement-support/>

bereavement support helpline 0808 802 6868

email: support@lullabytrust.org.uk

Calls to the helpline are free from all landlines and most mobile phone networks. The helpline is open 10am-5pm from Monday to Friday and 6pm-10pm on weekends and public holidays. They are also open on Tuesday and Thursday evenings from 7pm to 9pm.

The Lullaby Trust raises awareness of sudden infant death syndrome (SIDS), provides expert advice on safer sleep for babies and offers emotional support for bereaved families

◆ **Scottish Cot Death Trust** <https://scottishcotdeathtrust.org/>

0141 357 3946

email: contact@scottishcotdeathtrust.org

The Scottish Cot Death Trust is the only charity in Scotland dedicated to the sudden unexpected death of babies and young children.

◆ **Cruse Bereavement Care** <https://www.cruse.org.uk/>

Helpline 0808 808 1677

Email: helpline@cruse.org.uk

The helpline is open Monday-Friday 9.30-5pm (excluding bank holidays), with extended hours on Tuesday, Wednesday and Thursday evenings, when they are open until 8pm.

Many local branches of Cruse offer individual or group support for bereaved children. Cruse has a special website for young people.

<https://www.hopeagain.org.uk/> A special feature of this site is a message board where young people can share their experiences and receive replies from trained young supporters.

◆ **Cruse Bereavement Care (Scotland)**

<http://www.crusescotland.org.uk/>

Helpline: Freephone 0808 802 6161

email: support@crusescotland.org.uk

Offers support to anyone who has suffered a bereavement.

◆ **Way, Widowed And Young**

<https://www.widowedandyoung.org.uk/>

Join via their website and you will access to a members' only phone number. WAY is the only national charity in the UK for people aged 50 or under when their partner died. It's a peer-to-peer support group operating with a network of volunteers who have been bereaved at a young age

themselves, so they understand exactly what other members are going through.

“ Do not listen to other people telling you how you should feel and what you should (or should not) be doing. If it seems right to take your other children to McDonalds, the day after the death or even on the day of the funeral - DO IT! It's not about other people, it's about you as a family. ”

- ◆ **NHS bereavement support link** <https://www.nhs.uk/conditions/stress-anxiety-depression/coping-with-bereavement/>
- ◆ **Breathing space (for people living in Scotland only)**
<https://breathingspace.scot/how-we-can-help/what-we-do/>
0800 83 85 87 Opening hours Monday-Thursday 6pm to 2am Weekend: Friday 6pm-Monday 6am
This service is for people in Scotland, that are feeling down and don't know where to turn.
- ◆ **PAMIS** <https://pamis.org.uk/resources/bereavement-and-loss/>
Scottish based charity PAMIS has a Bereavement and Loss Learning Resource Pack is for those supporting bereaved people with profound and multiple learning disabilities and their parents and carers (please note there is a charge for this).
- ◆ **Samaritans** <https://www.samaritans.org/>
Freephone helpline: 116 123
Email: jo@samaritans.org
Talk to someone. Open 24 hours, 365 days a year. When you call Samaritans, your number is not displayed to the volunteer. The phones they use don't have caller display information on them. They might ask your name, because it's a natural question to ask in a conversation, or because of something you have said to them, but you don't have to tell them if you prefer not to.
- ◆ **BrakeCare** <http://www.brake.org.uk/>
0808 8000 401
Email: helpline@brake.org.uk
Support following a road death or injury. Brake's helpline offers support to people bereaved or seriously injured by road crashes and their carers. It also produces information and care books.
- ◆ **INQUEST** <https://www.inquest.org.uk/>
020 7263 1111
Email: inquest@inquest.org.uk
Inquest provides an independent and free legal advice service to bereaved families and friends on the inquest system. It offers special advice to lawyers, bereaved people, advice agencies, policy makers, the media and the general public on contentious deaths and their investigation.
- ◆ **Heavenly Gowns** <http://heavenlygowns.co.uk/gowns/>
Heavenly gowns UK is a not for profit organisation. It was set up to create beautiful outfits such as gowns, bonnets, nappies and wraps from donated wedding and other occasional dresses, for babies born too soon or sleeping.

SUPPORT FOR BEREAVED CHILDREN

◆ **Winston's wish**

<https://www.winstonswish.org/>

Freephone helpline: 08088 020 021

Email: ask@winstonswish.org

Winston's Wish is a charity that helps children deal with bereavement. There are sections on helping children with the grieving process, including online activities and a 'sky map' of memories where they can remember their loved ones. The helpline helps parents and children with the process of loss.



◆ **Jigsaw** (SouthEast) <https://www.jigsawsoutheast.org.uk/>

Helpline: 01342 313895

Email: info@jigsawsoutheast.org.uk

Information, advice and guidance to help support bereaved children and young people and those facing the loss of a loved one. They support families across Surrey, West Sussex and surrounding areas.

◆ **Grief Encounter** <https://www.griefencounter.org.uk/>

0808 802 0111 Mon-Fri 9am-9pm

Email: contact@griefencounter.org.uk

Support for bereaved children and their families to help alleviate the pain caused by the death of someone close. Services are free.

◆ **Hope again** (Cruse for young people)

<https://www.hopeagain.org.uk/>

0808 808 1677 (Mon-Fri, 9:00am-5:00pm)

Support for children and young people affected by the death of someone close.

"How do you spell 'love'?"

- Piglet

"You don't spell it...you feel it."

- Pook"

A.A.Milne



◆ **Edwards Trust** <http://edwardstrust.keanebuild19.uk/home/>
Bereavement line: 0121 454 1705
Email: admin@edwardstrust.org.uk
Offering support in the West Midlands to adults, children and young people who have had someone important to them die, or have a parent, significant carer, brother, sister, other family member, or friend who is terminally ill.

◆ **Sibs** tinyurl.com/ddh7b2hw
@Sibs_uk
Support for adult siblings suffering bereavement.

“ I'm getting through the days by just walking and visiting my sons grave. There are days when I struggle to get out of bed and my blinds don't get opened. I think of him all the time. I can't tell you how you get over it as I don't think you ever do. You just learn to live a different life.”

SUPPORT FOR PEOPLE WITH DISABILITIES/ LEARNING DISABILITIES AND/OR AUTISM

◆ **Sense**
<https://www.sense.org.uk/support-us/campaigns/when-im-gone/>
Sense have guides available to download on planning for the future, where you will live, what will happen, etc.

◆ **Respond** <https://respond.org.uk/>
0207 383 0700
email: admin@respond.org.uk
This service supports family members of people with learning disabilities, autism or both, who have experienced loss, harm or institutional abuse.

◆ **Prof. Irene Tuffrey-Wijne** <http://www.tuffrey-wijne.com/>
Kingston University & St George's, University of London
Faculty of Health, Social Care and Education
Cranmer Terrace, London SW17 0RE
Email: I.Tuffrey-Wijne@sgul.kingston.ac.uk
@TuffreyWijne

◆ Breaking bad news to people with intellectual disabilities
<http://www.breakingbadnews.org/>
A Professor of Intellectual Disability and Palliative Care, Prof. Tuffrey-Wijne has many years of experience of working with and supporting people with learning disabilities. She has written books on a variety of different associated subjects and runs a Grassroots project with people with learning disabilities.

◆ **PCPLD Network** <https://www.pcpld.org/>

Email: info@pcpld.org @PCPLDnetwork

The PCPLD Network is a charity aiming to raise awareness of the palliative care, end of life care and bereavement support needs of people with learning disabilities. It is run by a group of palliative care and learning disability professionals, with a Specialist Advisory Group including family carers and people with learning disabilities. Their website has a resource section with links to useful information. Membership is free. They host regular webinars and podcasts on topics including bereavement, available on their YouTube channel

https://www.youtube.com/channel/UCOQLenTftiiC_cFo0aaE-IA/videos

Other more local bereavement and loss services can be contacted via GP's, hospitals, funeral directors, libraries, churches etc.

MEMORIAL WEBSITE

◆ **Much Loved** <https://www.muchloved.com/>

Create your own special memorial website in tribute to your loved one, where you can share memories, thoughts and stories with family and

“ The one thing that helped me most was going out for a walk. It might seem simple, but grief is so debilitating that the thought of going out for a walk can seem like trying to climb a mountain. I used to walk somewhere quiet where I was unlikely to meet many people who knew me; so if I cried it was ok because no one could see me. The thing about moving is that it helps, it really does, it just makes facing the day the tiniest bit easier.

Self-care is paramount. Don't force yourself to do things that you are just not up to doing. It will be the simple things that help when the days ahead are tough. Like a warm cup of hot chocolate and a blanket to cuddle up to on the worst days.

Take the time to sort through your child's things. People will be anxious for you to get this over with quickly so that you can get back to "normal"! What they don't understand is that your life will never be that version of normal again. So be firm, if you are not ready to do it, leave it until you are. It took me nearly 5 years to start making memory blankets from my child's clothes. I gave myself the time and space to think about what I wanted to make and how I would achieve it.

Take your time when choosing their grave stone. It is the last thing you will do for your child so take as long as you can to get it right. You don't come out of the shock of grief for quite a while so decisions you make while still in shock will not be the same as those you make when the shock wears off. You don't want to add regret to the grieving process.”

FUNERAL FUNDING

◆ **UK Government funeral payments**

<https://www.gov.uk/funeral-payments>

For a child:

<https://www.gov.uk/child-funeral-costs>

Information on how to apply for funding towards the cost of a child or adult funeral.



◆ **Child funeral charity** <https://childfuneralcharity.org.uk/>

01480 276088

The Child Funeral Charity (CFC) assist families financially in England and Wales, who have to arrange a funeral for a baby or child aged 16 or under. Whilst many funeral directors, the clergy and most celebrants do not charge fees, there are other funeral related expenses that bereaved parents struggle to find. Financial support is available from them to help with such funeral costs, together with practical advice and guidance.

◆ **Bereavement Advice Centre**

<https://www.bereavementadvice.org/>

Freephone 0800 634 9494 Mon to Fri, 9am - 5pm

Lots of information on what to do when someone dies

How to arrange and pay for a funeral

<https://bereavementadvice.org/topics/the-funeral/paying-for-a-funeral>

◆ **Tell Us Once**

<https://www.gov.uk/after-a-death/organisations-you-need-to-contact-and-tell-us-once>

Tell Us Once is a free government service that allows you to report a death when you suffer a bereavement and need to tell central and local government. When someone has died, there are lots of things that need to be done, at a time when you probably least feel like doing them. This will include contacting Government departments and local council services that need to be informed e.g. Passport office, DVLA, Council and Personal Tax. You will need to contact your Register Office in advance of using the Tell Us Once service which will normally be when you register the death. The Registrar will then advise you how to use the service.

WILLS AND TRUSTS

◆ **Mencap**

<https://www.mencap.org.uk/advice-and-support/wills-and-trusts-service>

Contact Gina on 0207 696 6925

Email: willsandtrusts@mencap.org.uk

Mencap has some useful advice on wills and setting up a trust. They also run Planning for the Future seminars all over England throughout the year.

“ *Your children will grieve too but in a different way. Keep the channels of communication open between you and them because nearly everyone else is focused on you and how you are doing. People put a lot of pressure on children to look after their parents after such a huge loss that the children's grief gets forgotten. Children are not known as the forgotten grievers for nothing.*

With great pain comes great beauty. I remember being in awe of the beautiful sunsets I would see or the beauty of nature that up 'til then I hadn't really taken the time to stop and look at.

Society as a whole doesn't handle grieving people very well. Expect people to say after only a few months "it's really that bad still, you're not over it yet?". Shocking to hear, especially when your heart is so broken. Regardless of what family, friends and strangers' uninvited opinions on your grief are, you have permission to mourn the loss of your child. You will grieve them until you yourself take your last breath.

There is no right or wrong way to grieve. Whatever brings you comfort, unless of course it is causing you harm. ”

BOOKS

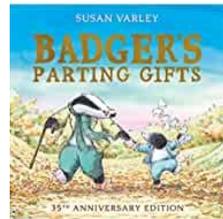
◆ Jessica Kingsley Publishers

<https://www.jkp.com/uk/catalogsearch/result/?q=bereavement>
020 7833 2307 Email: hello@jkp.com

For children

◇ **Badgers parting gifts** by Susan Varley

The tale of a dependable, reliable and helpful badger who realises that his old age will soon lead to death. His friends learn to come to terms with his death in an enchanting tale.



◇ **The lonely tree** by Nicholas Halliday

The Lonely Tree is a charmingly illustrated picture book which will help children and their families in times of loss or change with the gentle reassurance that saying goodbye is a natural part of life.

◇ **Always and Forever** by Alan Durant

When Fox dies the rest of his family are absolutely distraught. How will Mole, Otter and Hare go on without their beloved friend? But, months later, Squirrel reminds them all of how funny Fox used to be, and they realise that Fox is still there in their hearts and memories.



◇ **The Invisible String** by Patrice Karst

Helping readers of all ages across the world cope with separation anxiety, loss, loneliness, and grief.

◇ **The Memory Tree** by Britta Teckentrup

Fox has lived a long and happy life in the forest, but now he is tired. He lies down in his favourite clearing, and falls asleep for ever. Before long, Fox's friends begin to gather in the clearing. One by one, they tell stories of the special moments that they shared with Fox. And so, as they share their memories, a tree begins to grow, becoming bigger and stronger with each memory, sheltering and protecting all the animals in the forest, just as Fox did when he was alive. This gentle story about the loss of a loved one is perfect for sharing and will bring comfort to both children and parents.

All of the above titles are available from Amazon and other booksellers.

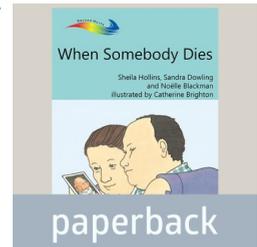
◆ **Books beyond words** <https://booksbeyondwords.co.uk/>

020 7492 2559 (*During the coronavirus outbreak staff are working from home and this phone number will not be manned*)

Email: admin@booksbeyondwords.co.uk

Beyond Words is a charity that provides books and training to support people who find pictures easier to understand than words. There are a variety of different titles but for the purposes of this guide, these are the most relevant. Some are electronic (e) books. Some of the pictures are available for free, including their coronavirus guides, but there is a charge for the full (e) books.

- * When Somebody Dies
- * Am I Going to Die?
- * When Dad Died
- * When Mum Died



◆ **National Bereavement Alliance**

<https://nationalbereavementalliance.org.uk/>

@bereavementNBA

A guide full of ideas of support entitled 'Keeping in touch when you can't be with someone who may die'. This guide includes ideas for both children and adults.

POEMS

Poetry can help put thoughts into perspective. If you have suffered a loss and are looking for a poem for a loved one's funeral, memorial, or loss here are a couple of useful weblinks.

Family friend poems

◆ **In memory**

<https://www.familyfriendpoems.com/poems/death/in-memory/>

◆ **Poems to help cope with grief and loss**

<https://www.familyfriendpoems.com/poems/death/grief/>

BEREAVEMENT SUPPORT IN COUNTRIES (OUTSIDE OF THE UK)



Australia

◆ **SANDS Australia** <https://www.sands.org.au/>
General Enquiries

* VIC Telephone: 03 8595 2400

* QLD Telephone: 07 3254 3422

24/7 Phone Support Telephone: 1300 072 637

Email: support@sands.org.au

Sands is a volunteer-based organisation providing individualised care from one bereaved parent to another, giving them

support and hope for the future, following the death of a baby.

◆ **Red nose grief and loss** <https://rednosegriefandloss.org.au/>

Talk in person, 24 hours a day, call 1300 308 307

Red Nose Grief and Loss website is a support service provided by Red Nose (formerly SIDS and Kids).

◆ **The Compassionate Friends Australia** <https://tcfa.org.au/>

Supporting families when a child dies.

Canada

◆ **Angel whispers** <http://www.angelwhispers.ca/angelwhispers/>

Office Phone: 780-998-5595 ext 225 Cell: 780-974-7054

Confidential email: angelwhispers@familiesfirstsociety.ca

Angel Whispers is a service for parents who have lost a baby shortly after birth, or during pregnancy; through miscarriage, molar or ectopic pregnancy, or stillbirth.

◆ **Baby's Breath** <https://www.babysbreathcanada.ca/>

National: 800 363-7437

Local: 905 688-8884

Email: info@babysbreathcanada.ca

Baby's Breath is Canada's national foundation focused on SIDS, and more recently also dedicated to reducing all sudden and unexpected infant deaths including stillbirths.

Ireland

◆ **Anam Cara** <https://anamcara.ie/>

Bereavement support for parents and siblings Ireland

0035 3 (1) 4045378

An all-Ireland organisation providing online and face to face support services for bereaved parents and siblings.

◆ **FirstLight** <https://firstlight.ie>

24-hour helpline 1850 391 391

Email: support@firstlight.ie

A bereavement support service for parents and families anywhere in Ireland who experience the sudden loss of an infant or young child.

USA

◆ **The MISS Foundation** <https://missfoundation.org/>

602-279-MISS (6477)

888-455-MISS (6477)

email: info@missfoundation.org

A volunteer based organisation providing C.A.R.E. (counselling, advocacy, research, and education) services to families experiencing the death of a child.

◆ **The Compassionate Friends**

<https://www.compassionatefriends.org>

Phone: 630.990.0010

Toll Free: 877.969.0010

Email:

nationaloffice@compassionatefriends.org

Offers mutual assistance, friendship and understanding to families following the death of a child of any age.

Provides information on the grieving process, referrals to local chapter meetings, and publishes a quarterly magazine



◆ **Bereaved Parents of the USA**

<https://www.bereavedparentsusa.org/>

Phone: 630-971-3490

Email: president@bereavedparentsusa.org

Helping grieving parents and families rebuild their lives after the death of a child. Please visit their website to find your nearest chapter.

◆ **A.M.E.N.D.** <https://www.amendgroup.com/>

Centering <https://centering.org/>

866-218-0101 M-F 9am-4pm CDT (Central Daylight Time)

Email: centeringresources@gmail.com

Offers support and encouragement to parents having a normal grief reaction to the loss of their baby. Provides one-to-one peer counseling with trained volunteers and lots of grief resources like books and care packages.

“ If there is one thing I would like to say to a family who has lost a child, is just be yourself. Be true to your feelings, be sad, be angry, be numb, be unable to talk. But above all, don't try to be strong for others. It's your grief, you need to deal with it in your own personal way. I want and need people to say my daughter's name, I want her life to always be remembered....always. Grief never goes away; we just learn to live with it in our own individual way. Accept that some people will always say “oh I know how you must be feeling” ...but in truth no one can unless they have lost a child. It's a club no parent wants to join, but unfortunately some of us do.”

◆ **SHARE: Pregnancy and Infant Loss Support, Inc.**

<http://www.nationalshareoffice.com/>

1-(800)-821-6819 or (636) 947-6164

Email: share@nationalshareoffice.com

Mutual support for bereaved parents and families who have suffered a loss due to miscarriage, stillbirth or neonatal death. Provides newsletter, pen pals, information re: professionals and pastoral care. Chapter development guidelines. Online message board and weekly chatrooms.

◆ **UNITE, Inc.** <http://www.unitegriefsupport.org/>

Voice: 1-888-488-6483 Email: administrator@unitegriefsupport.org

Support for parents grieving a miscarriage, stillbirth or infant death. Also provides support for parents through subsequent pregnancies. Group meetings, phone help, newsletter, lending libraries and annual conference. Offers guidelines for starting and facilitating a group. Grief counselor training programs. Professionals in advisory roles.

◆ **HEALING HEART** <http://www.healingheart.net/>

Email: support@healingheart.net

Healing heart is for Bereaved Parents is dedicated to providing grief support and services to parents who are suffering as the result of the death of their child or children.

◆ **Alive Alone, Inc.** <http://www.alivealone.org/>

Email: alivalon@bright.net

Facebook: <https://www.facebook.com/Alive-Alone-111592388893157>

National network. Founded 1988. Self-help network of parents who have lost an only child or all of their children. Provides education and publications to promote communication and healing, to assist in resolving grief and to develop means to reinvest lives for a positive future. Bimonthly newsletter.

LOOKING AFTER YOURSELF

Although you won't feel like it, it is really important to look after yourself. You will at times just feel like you don't want to get out of your pyjamas, that is fine. Just make sure to eat nutritiously and drink plenty of fluids to keep your strength up. There are several ways that you can help look after yourself. Talking to others that have experienced loss, practising your faith or a hobby, walking, exercise, meditation and mindfulness. Try not to keep your emotions to yourself, it is good to cry, scream or yell, but not so good to bottle things up. Here are some useful links to explore.....

◆ **Headspace** <https://www.headspace.com/mindfulness>

◆ **Mindful**
<https://www.mindful.org/meditation/mindfulness-getting-started/>

◆ **WALKING FOR HEALTH**
<https://www.walkingforhealth.org.uk/>

We have a guide in our practical guides series on Carers wellbeing, with other ideas on how to look after yourself. It also includes more links on counselling and mental health support. You can download it from our website:
<https://www.rarechromo.org/practical-guides-for-families/>

“ *Of all the losses, child loss is the most tough. It is not the natural order of things and so it is so out of the ordinary. A grieving parent reminds the rest of the world that the worst can actually happen to them and because of this, many people will go out of their way to avoid seeing you and talking about your child. This is a "them" problem and not a "you" problem. When your child dies, your world implodes and you have to learn to navigate the world in a different way from before. It's like you've landed on an alien planet and no one understands the language you speak.*

Love doesn't end when your child dies. It grows stronger with their absence therefore the pain doesn't ease, but you learn to move forward, bringing your child with you, loving them, talking about them, keeping their memory alive. It will be a very different life to the one you had before; but it can still be meaningful and beautiful. Your world is forever split into two parts: before and after.”

More parent quotes.....

“ I would say that one of the most important things to do is to realise that everyone grieves differently - even (or especially) couples and so it is important to cut each other some slack. Just because one wants to sit at home and cry, it doesn't mean that because the other one wants to go to the cinema (likely to get absorbed in something else), that they are not actually going through the same emotions (strange though that might sound). ”

“ I read a very good book which I lent to someone a while back. It was called 'Past Caring' and was by a woman called Audrey Jenkinson, who had been the main carer for both her parents (not quite the same) but it did have some useful general advice as well. Her main point was to remember that everyone grieves differently - it got me through some tricky times when my husband didn't seem to see things in quite the way I did and I suppose it meant that I did a lot more compromising than he did (and probably still do), but we are still together and still both able to remember our daughter with love and gratitude. We also still celebrate her Birthday every year with cake - usually a children's chocolate one from the supermarket and quite often caterpillar shaped! ”

“ Talk about the child who has died too, still include them as part of the family, and if there are other children in the family, don't be afraid to cry in front of them. My friend was unexpectedly widowed before she was 40 and had two young children, she did her best to hide her tears from them and as a result they grew up thinking that she didn't really care for their dad. Fortunately, (or unfortunately), it took counselling to find this out, by which point it was a bit late. ”

“ My daughter wasn't expected to live long when she was born, something I read early on in our journey (and I can't remember if it was Unique or SOFT) was 'don't be afraid to love your child' and I would agree with that. I did spend quite a lot of time in that first year almost waiting for her to die and I wish I'd relaxed a bit more and enjoyed the year for what it was. ”

In loving memory.....



If there ever comes a day when we can't be together,
Keep me in your heart, I'll stay there forever.
— Winnie the pooh



Inform Network Support



Understanding Chromosome & Gene Disorders

Rare Chromosome Disorder Support Group
The Stables, Station Road West, Oxted, Surrey RH8 9EE,
United Kingdom
Tel: +44(0)1883 723356
info@rarechromo.org | www.rarechromo.org

Join Unique for family links, information and support.

Unique is a charity without government funding, existing entirely on donations and grants. If you can, please make a donation via our website at www.rarechromo.org
Please help us to help you!

Our thanks to all of the parents that contributed towards this guide.

This guide was compiled by Unique and reviewed by:

Prof Irene Tuffrey-Wijne

Professor of Intellectual Disability & Palliative Care

Faculty of Health, Social Care & Education, Kingston and St. George's

A joint enterprise of Kingston University and St. George's, University of London, 6th floor Hunter Wing, Cranmer Terrace, London SW17 0RE, UK

Email: I.Tuffrey-Wijne@sgul.kingston.ac.uk

Website: <http://www.tuffrey-wijne.com/>

Version 1 (MM)

Copyright © Unique 2021

Rare Chromosome Disorder Support Group Charity Number 1110661
Registered in England and Wales Company Number 5460413