The Highland Council
Comhairle na Gàidhealtachd

NHS Highland

Children's Hospices Across Scotland

Crocus Group

Life Limiting Conditions, Palliative Care, Loss and Bereavement, Trauma, and Tragic Incidence Information

Introduction

The purpose of this collection of information is to link parents and professionals to a range of websites and information on issues they may be dealing with or having to prepare for.

The following documents and PDF files are designed to give Schools initial information and to offer links to details of support and advice available on the following subjects: to decide which descriptor to use

- Children and young people with exceptional health care needs
- Children and young people with life limiting conditions and palliative care needs
- Self-harm
- Suicide
- Sudden unexpected death
- Cot death and neonatal death
- Bereavement and grief

These resources are not exhaustive but were deemed as good sources of information at the time of publication.

Guiding Principles

Best practice will be achieved by providing schools and families links to the information they may to fully support children and young people with a range of additional support needs.

This pack was created by a small working group:
Fiona Reid – Diana Children's Nurse, Children's Hospices Across Scotland
Jane Baines – Development Officer Additional Support Needs (ASN)
Hannah Lind – CROCUS
Fiona Shevill – Social Worker
Maudie Riley – ASN Instructor
Derek Brown - NHS Highland Chaplaincy

The group also consulted with the following and would like to thank them for their input:
Educational Psychologists
Primary Mental Health Workers
CROCUS
CHAS
Claire McCall –Raigmore Hospital Bereavement Officer

This version updated March 2018

Appendix 1

RESPONDING TO TRAGIC EVENTS GUIDANCE FOR SCHOOLS: WORKING WITH THE PSYCHOLOGICAL SERVICE

This policy was written in response to tragic events in Scotland; it contains some guidance and information for the immediate aftermath of a tragic incident in order to provide help and advice quickly.
There is a link within this section to the full document.

Contents Page

Policy Links

Schools may find in helpful to refer to the following Highland Council Policies and legislation when planning to meet the additional support needs of pupils:

- Moving and Handling -
  http://www.highland.gov.uk/staffsite/info/8/health_and_safety/60/policies

- Intimate Care -
  http://www.highland.gov.uk/downloads/file/155/intimate_care_for_children_and_young_people

- The Administration of Medicines -
  http://www.highland.gov.uk/downloads/file/175/administration_of_medicines_in_schools

- The Highland Practice Model -
  http://www.forhighlandschildren.org/5-practiceguidance/high-pract-model.pdf

- Equalities Act -
  https://www.gov.uk/guidance/equality-act-2010-guidance

- Promoting Positive Behaviour -
  http://www.highland.gov.uk/download/downloads/id/165/positive_behaviour_policy.pdf

- Children absent from school through ill health -
  http://www.gov.scot/Resource/Doc/158331/0042883.pdf

- Tragic events guidance see Appendix 1

Table of Local Contacts

Health			
Highland Bereavement Service	Via Raigmore Hospital switchboard	Diana Children's Palliative Care Nurse	07879 441948
Cystic Fibrosis Nurse Specialist	01463701332	Hospital switchboard	01463 704000
Epilepsy Nurse Specialists	01463 701322	Hospital Chaplain	Via Raigmore Hospital switchboard
Community Children's Nurses	01463 701340	Oncology nurse specialists	01463 701350
Care and Learning - Social Care			
Complex Needs social worker	01463 701376	Oncology social worker	01463 701376
Orchard respite	01463 714165		
Care and Learning - Education			
	07717680906	Development Officer ASN	
	01463 233494	Psychological Services	
	01349 868546	PMHW	
Voluntary sector			
Crocus bereavement group (for children)	01463 714568 07470 364999	CHIP+ (Children in Highland Information Point)	01463 711189
Children's Hospices Across Scotland	Rachel House Hospice: 01577865777 CHAS at Home, Inverness: 01463 248479		

Children with life-limiting conditions in school

Introduction

Modern society expects adults to die but expects children and young people to live to full adulthood, and so the diagnosis of a life limiting disorder has a major impact on any child, adolescent or young adult, as well, of course, as their family, and also their friends and the professionals caring for them. Many illnesses requiring palliative support in this age group are familial and, as a result, more than one child in the family may be affected, which complicates the situation yet further.

The alternative name for 'life-limiting' is '**palliative**', although the journey may be over many years. The word palliative however is not a language with which many parents and children would feel comfortable so should **not** be used in the school environment. Palliative care is also often misperceived as being only about end of life or terminal care.

"Palliative care for children and young people with life-limiting conditions is an active and total approach to care, from the point of diagnosis or recognition, embracing physical, emotional, social and spiritual elements through to death and beyond. It focuses on enhancement of quality of life for the child/young person and support for the family and includes the management of distressing symptoms, provision of short breaks and care through death and bereavement.(2008)

School is a place of normality, with all children having a right to education in the UK. It is a place of learning across the whole spectrum of academia, social interaction and responsibility, moral behaviours and preparation for the future. For some children with a life-limiting illness it may be their sole source of peer interaction. Creating a balance between stretching and maximising learning within the school and meeting the demands of ever changing achievable goals can be a challenge. Indeed flexibility and innovative thinking in partnership with family and other professionals is the key. One of the aims of education is to advance learning and skills over time, but some children with life-limiting conditions may progressively lose functional and communication skills such that learning may appear to regress rather than advance. This can be a difficult concept for staff where targets appear to be repeatedly unmet. All children with palliative care needs should have a Lead Professional in addition to the Named Person, and should have a Highland Practice Model Child's Plan which may need to incorporate an Individual Education Plan.

The ability of any one child to focus and concentrate for long periods may be impacted such that length and timing of attendance may need to be reviewed to meet the child's best attention/functionality times and the best opportunities to meet with curricular targets. School transport may need to be adjusted and any personnel required to assist with transport should receive appropriate training.

Teenagers tend to think for the 'now' and will maintain hope of achieving even if this appears unrealistic.

Many children will also require increasing medical management in the school environment which will cause anxiety amongst staff, and training should be requested in advance especially at times of year transitions.

Some children will also have siblings who take on a level of caring responsibilities in the home, and who will be impacted by uncertainty, family upheaval, and worry for the health and welfare for their brother/sister in the future.

Anticipatory grieving

The changes in their child's condition, regression in skills, constantly moving goals and achievements present as 'loss' to parents and siblings for which there is a grieving process. Parents may present as resistant, angry, and distressed with intermittent breakdown in relationships between family members and medical/school professionals. This is normal and represents losses that are from the past, present and those to come. Giving parents the opportunity, space and time to talk and process this is essential. Partnership working between professionals is paramount to ensuring all are clear about plans and information given to the family.

Anticipatory care plans

Some children will have a very specific healthcare plan in addition to the Child's Plan. These are medically orientated and focus on management in the case of deterioration or death. The information can be very sensitive and therefore is only released on a 'need to know' basis, although some parents may wish school to hold a copy. These plans are always held by GPs.

Children and Young People's Acute Deterioration Management plan (CYPADM)

This is a form that gives hospital ward, A&E and ambulance staff direction on resuscitation in event of cardiac or respiratory arrest (like an adult CPR form). Some children may hold a completed form. School staff should familiarise themselves with the content in order to remind ambulance services of its content should they be called to attend school. Support and guidance can be made available to schools. This document reflects the needs of a child/young person and their views are paramount and should be followed. Form can be viewed at http://www.gov.scot/Health

Children's Hospices Across Scotland

There are two children's hospices in Scotland (Rachel House in Kinross and Robin House in Balloch). The hospice also has CHAS at home teams who can deliver care locally based from both houses, and also from bases in Inverness and Aberdeen. Types of support for referred families include emotional and social support, medical and nursing care, symptom management review, short respite in the home, and respite breaks in the hospices. CHAS also supports end of life care either in the hospice, hospital or at home, with follow up bereavement support for the whole family and siblings.

Staff support and boundaries

This is a challenging time for all concerned whereby staff can potentially become emotionally overinvolved or alternatively they feel they need to keep healthy boundaries. Staff should speak to their senior managers to request help if they are finding the situation difficult to manage. Families will reach out to those who befriend them so that it is up to professionals to ensure their relationship remains at a professional, yet supportive level. Head teachers should be aware that PSAs may be particularly vulnerable as they often work with children on a 1:1 level. Respite care in the home is often difficult to obtain and retain such that PSAs may be approached to carry out this roll in addition to school hours. Care must be taken to ensure that they are not conflicted between family roles and school professional standards, do not exceed safe working hours, and recognise where their indemnity insurance cover lies when working outside the school. Families trying to access support should seek help through the child’s plan process.

Should there be a general atmosphere and recognition within the school teams of staff being stressed by the situation then external support from others should be sought (Diana Children’s Nurse, specialist nurses, Educational Psychology).

Sources of support

See suggested websites (SEND project via Together for Short Lives, SeeSaw, Children’s Hospices Across Scotland Beacon Hill school policy)

Complex Health Needs, Types of Conditions

There are a large number of life-limiting conditions which can affect children and young people. Currently in Highland there are pupils with a wide range of different conditions. The websites Together for Short Lives, Contact a Family, and Rare Diseases UK contain clear information on a range of conditions. The following are brief descriptors of some of the more common conditions

Metabolic Disorders

Individual inborn or congenital errors of metabolism are very rare. However, more than 1400 inherited metabolic diseases have been described. Many of these disorders are potentially treatable via diet and/or drug therapy. It is essential that a rapid accurate diagnosis be made to ensure rational treatment, correct genetic advice and future antenatal diagnosis.

There are currently 700 known metabolic disorders. There are a number of pupils in Highland with a number of different metabolic disorders.

Niemann-Pick Disease

What is Niemann-Pick Disease?

Niemann-Pick disease (NP) refers to a group of inherited metabolic disorders known as lipid storage diseases. Lipids (fatty materials such as waxes, fatty acids, oils, and cholesterol) and proteins are usually broken down into smaller components to provide energy for the body. In Niemann-Pick disease, harmful quantities of lipids accumulate in the brain, spleen, liver, lungs, and bone marrow. Neurological symptoms may include ataxia (lack of muscle control during voluntary movements such as walking), loss of muscle tone, brain degeneration, increased sensitivity to touch, spasticity (stiff muscles and awkward movement), and slurred speech. Other symptoms may include feeding and swallowing difficulties, eye paralysis, learning problems, and an enlarged liver and spleen. There may be clouding of the cornea and a characteristic cherry-red halo develops around the centre of the retina. The disease has three categories. Type A, the most severe form, occurs in early infancy and is seen primarily in Jewish families. It is characterized by progressive weakness, an enlarged liver and spleen, swollen lymph nodes, and profound brain damage by six months of age. Children with this type rarely live beyond 18 months. Type B usually occurs in the pre-teen years, with symptoms that include ataxia and peripheral neuropathy. The brain is generally not affected. Other symptoms include enlarged liver and spleen, and pulmonary difficulties. In types A and B, insufficient activity of an enzyme called sphingomyelinase causes the build-up of toxic amounts of sphingomyelin, a fatty substance present in every cell of the body. Type C may appear early in life or develop in the teen or adult years. It is caused by a lack of the NPC1 or NPC2 proteins. Affected individuals may have extensive brain damage that can cause an inability to look up and down, difficulty in walking and swallowing, and progressive loss of vision and hearing. There may be moderate enlargement of the spleen and liver. Individuals with Type C who share a common ancestral background in Nova Scotia were previously referred to as Type D.

Is there any treatment?

There is currently no cure for Niemann-Pick disease. Treatment is supportive. Children usually die from infection or progressive neurological loss. There is currently no effective treatment for persons with type A. Bone marrow transplantation has been attempted in a few individuals with type B. The development of enzyme replacement and gene therapies might also be helpful for those with type B. Restricting one's diet does not prevent the build-up of lipids in cells and tissues. For more information see http://www.niemann-pick.org.uk/

Maple Syrup Urine Disease

What is MSUD?

This metabolic disease is named for the presence of sweet-smelling urine, with an odor similar to that of maple syrup, when the person goes into metabolic crisis. The smell is also present and sometimes stronger in the ear wax of an affected individual at these times. Infants with this disease seem healthy at birth but quickly deteriorate, often with severe brain damage, which may be permanent. Without prompt treatment they will die from brain swelling.

Untreated, and during times of metabolic crisis, symptoms of the condition include anorexia, vomiting, dehydration, lethargy, hypotonia, seizures, hypoglycaemia, ketoacidosis, opisthotonus, pancreatitis, rapid neurological decline, coma and cerebral oedema.

Management

Keeping MSUD under control requires careful monitoring of blood chemistry, both at home and in a hospital setting. DNPH or specialised dipsticks are used to test the patient's urine for ketones (a sign of metabolic decompensation), when metabolic stress is likely or suspected. Fingerstick tests are performed regularly and sent to a laboratory to determine blood levels of leucine, isoleucine and valine. Regular metabolic consultations, including blood-draws for full nutritional analysis, are recommended; especially during puberty and periods of rapid growth. MSUD management also involves a specially tailored metabolic formula, a modified diet, and lifestyle precautions such as avoiding fatigue and infections, as well as consuming regular, sufficient calories in proportion to physical stress and exertion. Without sufficient calories, catabolism of muscle protein will result in metabolic crisis. Those with MSUD must be hospitalised for intravenous infusion of sugars and nasogastric drip-feeding of formula, in the event of metabolic decompensation, or anorexia, diarrhoea or vomiting. Food avoidance, rejection of formula and picky eating are all common problems with MSUD. Some patients may need to receive all or part of their daily nutrition through a feeding tube.

A diet with carefully controlled levels of the amino acids leucine, isoleucine, and valine must be maintained at all times in order to prevent neurological damage. Since these three amino acids occur in all natural protein, and most natural foods contain some protein, any food intake must be closely monitored, and day-to-day protein intake calculated on a cumulative basis, to ensure individual tolerance levels are not exceeded at any time. As the MSUD diet is so protein-restricted, and adequate protein is a requirement for all humans, tailored metabolic formula containing all the other essential amino acids, as well as any vitamins, minerals, omega 3 fats and trace elements (which may be lacking due to the limited range of permissible foods), are an essential aspect of MSUD management. These complement the MSUD patient's natural food intake to meet normal nutritional requirements without causing harm.[9] If adequate calories cannot be obtained from natural food without exceeding protein tolerance, specialised low protein products such as starch-based baking mixtures, imitation rice and pasta may be prescribed, often alongside a protein-free carbohydrate powder added to food and/or drink, and increased at times of metabolic stress. Some patients with MSUD may also improve with administration of high doses of thiamine, a cofactor of the enzyme that causes the condition.

Usually MSUD patients are monitored by a dietitian. Liver transplantation is another treatment option that can completely and permanently normalise metabolic function, enabling discontinuation of nutritional supplements and strict monitoring of biochemistry and caloric intake, relaxation of MSUD-related lifestyle precautions, and an unrestricted diet. This procedure is most successful when performed at a young age, and weaning from immuno-suppressants may even be possible in the long run. However, the surgery is a major undertaking requiring extensive hospitalisation and rigorous adherence to a tapering regime of medications. Following transplant, the risk of periodic rejection will always exist, as will the need for some degree of lifelong monitoring in this respect. Despite normalising clinical presentation, liver transplantation is not considered a cure for MSUD. The patient will still carry two copies of the mutated BKAD gene in each of their own cells, which will consequently still be unable to produce the missing enzyme. They will also still pass one mutated copy of the gene on to each of their biological children. As a major surgery the transplant procedure itself also carries standard risks, although the odds of its success are greatly elevated when the only indication for it is an inborn error of metabolism. In absence of a liver transplant, the MSUD diet must be adhered to strictly and permanently. However, in both treatment scenarios, with proper management, those afflicted are able to live healthy, normal lives without suffering the severe neurological damage associated with the disease.
For more information see http://rarediseases.org

Other Disorders

Cystic Fibrosis

What is cystic fibrosis?

Cystic fibrosis (CF) is a life-limiting inherited condition caused by a faulty gene that controls the movement of salt and water in and out of cells. This causes mucus to gather in the lungs and digestive system and creates a range of challenging symptoms.

There is currently no cure for cystic fibrosis but many treatments are available to manage it, including physiotherapy, exercise, medication and nutrition. Each week five babies are born with cystic fibrosis, and two people die. More than half of the cystic fibrosis population in the UK will live past 41, and improved care and treatments mean that a baby born today is expected to live even longer.

CF and education

Although every child with CF is unique, and they will all respond to their illness, treatments and experiences in different ways. There are some common symptoms that may be particularly relevant at school. A noticeable feature may be a persistent cough, which can be worse during periods of infection. Although this is not infectious, it can be embarrassing in front of other children, particularly because a severe coughing attack can lead to coughing up mucus or vomiting.

People with CF should not meet in person because of the risk of cross-infection (passing on potentially harmful bugs), which is an important consideration if there is more than one pupil with CF at the school, or if they are receiving a visitor with cystic fibrosis.

If a child with CF is taking part in a school trip it may be necessary to consider how to manage their treatment, and to assess the cross-infection risk.

Treatment
Children with CF usually require daily physiotherapy, and might need parents or carers to come into the school to help them. Nebuliser treatment may also be necessary. The number of physiotherapy sessions needed each day depends on the child's health, and the length will vary from 15 minutes to an hour.

Meals
Cystic fibrosis can stop the pancreas working properly, so special enzyme supplements may need to be taken with all meals and snacks to help digest food. These are available in capsule form and are often taken in large quantities. Children with CF need to eat a very high calorie lunch that is high in protein, to compensate for the amount lost in stools due to the lack of pancreatic enzymes, and to help them fight chest infections. This may be a sensitive issue in schools that have adopted a healthy eating programme, as children with CF have different dietary requirements. It is important to make sure that children with CF adhere to their food and medication requirements, even when they do not want to.

Education
Children with CF are as academically able as their peers, and teachers should expect similar standards. Hospitalisation or chest infections can result in prolonged absence from school however, so extra help may be needed to catch up with the rest of the class. Examination boards make certain allowances for pupils with cystic fibrosis.

Some older children can use portable IV antibiotic equipment, which helps them attend lessons more regularly. Physical exercise is very good for children with CF, and they should join in games and PE lessons. Illness can result in loss of energy, which should be taken into consideration for both academic and sports activities.

Examinations
Although children with CF are as academically able as their peers, some may have additional support needs.

Cystic fibrosis can prevent or hinder a child from using certain educational facilities. Additional support arrangements need to be arranged with the SQA.

Social and psychological aspects
Children with CF may be teased or picked on at school because they can be underweight and small for their age, and might have a persistent cough. Taking tablets and capsules with meals and eating a different diet from classmates can also be embarrassing. Physiotherapy is time consuming, sometimes at the expense of a child’s social life, although children with cystic fibrosis often find supportive friends who help with care and physiotherapy. During teenage years there is a chance that children may

neglect their physiotherapy and diet. Some people with CF experience delayed onset of puberty, which may cause anxiety or insecurity. Teenagers may need sympathetic treatment and counselling to help them deal with some of these issues. For more information www.cysticfibrosis.org.uk

Friedreich's Ataxia

What is Friedreich's ataxia?

Friedreich's ataxia (also called FA or FRDA) is a rare inherited disease that causes nervous system damage and movement problems. It usually begins in childhood and leads to impaired muscle coordination (ataxia) that worsens over time. The disorder is named after Nicholaus Friedreich, a German doctor who first described the condition in the 1860s.

In Friedreich's ataxia the spinal cord and peripheral nerves degenerate, becoming thinner. The cerebellum, part of the brain that coordinates balance and movement, also degenerates to a lesser extent. This damage results in awkward, unsteady movements and impaired sensory functions. The disorder also causes problems in the heart and spine, and some people with the condition develop diabetes. The disorder does not affect thinking and reasoning abilities (cognitive functions).

Friedreich's ataxia is caused by a defect (mutation) in a gene labelled FXN. The disorder is recessive, meaning it occurs only in someone who inherits two defective copies of the gene, one from each parent. Although rare, Friedreich's ataxia is the most common form of hereditary ataxia, affecting about 1 in every 50,000 people in the United States. Both male and female children can inherit the disorder. For more information go to http://rarediseases.org or www.cafamily.org.uk

Epilepsy

What is epilepsy?

Around one in 240 children under 16 in the UK has epilepsy. With a few sensible precautions, most will be able to do the things other children can do. However, some children have more complex epilepsy and need specialist help and support.

Children can have different types of seizures, at different ages. In babies, seizures may not be obvious to an onlooker. Their seizures may show as changes in breathing patterns, or movements of their eyelids or lips. They may have bicycling movements of their legs, brief jerks or episodes of stiffening of their body and limbs. As their brain matures, older children have seizures that are more easily recognised, such as tonic-clonic seizures. Some babies and children can have several different types of seizures.

Children with epilepsy are at risk of seizure related injuries. Children who have epilepsy because of another condition, or have only recently been diagnosed with epilepsy are at highest risk. This is because they are more likely to be having seizures than other children.

Every year, around 40 to 80 children in the UK die because of their epilepsy. For example, a child could have a seizure in a dangerous place. Or the seizure itself may be the cause of death. But the reasons for these deaths are not always known. Where a child with epilepsy has died suddenly, and no reason can be found, it is called sudden unexpected death in epilepsy (SUDEP). For more information www.epilepsy.org.uk

Muscular Dystrophy

What is Muscular Dystrophy?

The muscular dystrophies (MD) are a group of inherited genetic conditions that gradually cause the muscles to weaken, leading to an increasing level of disability. MD is a progressive condition, which means it gets worse over time. It often begins by affecting a particular group of muscles, before affecting the muscles more widely. Some types of MD eventually affect the heart or the muscles used for breathing, at which point the condition becomes life-threatening. There's no cure for MD, but treatment can help to manage many of the symptoms.

What causes muscular dystrophy?

MD is caused by changes (mutations) in the genes responsible for the structure and functioning of a person's muscles. The mutations cause changes in the muscle fibres that interfere with the muscles' ability to function. Over time, this causes increasing disability. There are many different types of MD, each with somewhat different symptoms. Not all types cause severe disability and many don't affect life expectancy.

Some of the more common types of MD include:

- Duchenne MD – one of the most common and severe forms, it usually affects boys in early childhood; men with the condition will usually only live into their 20s or 30s.
- Myotonic dystrophy – a type of MD that can develop at any age; life expectancy isn't always affected, but people with a severe form of myotonic dystrophy may have shortened lives.
- Facioscapulohumeral MD – a type of MD that can develop in childhood or adulthood; it progresses slowly and isn't usually life-threatening.
- Becker MD – closely related to Duchenne MD, but it develops later in childhood and is less severe; life expectancy isn't usually affected as much.
- Limb-girdle MD – a group of conditions that usually develop in late childhood or early adulthood; some variants can progress quickly and be life-threatening, whereas others develop slowly.
- Oculopharyngeal MD – a type of MD that doesn't usually develop until a person is 50-60 years old, and doesn't tend to affect life expectancy.
- Emery-Dreifuss MD – a type of MD that develops in childhood or early adulthood; most people with this condition will live until at least middle-age.

Who's affected by muscular dystrophy?

In the UK, more than 70,000 people have MD or a related condition.
For more information www.musculardystrophyuk.org

Cornelia de Lange Syndrome (CdLS)

What is Cornelia de Lange Syndrome?

Cornelia de Lange Syndrome (CdLS) is a very rare genetic disorder present from birth, but not always diagnosed at birth. It causes a range of physical, cognitive, and medical challenges and affects both genders equally. The syndrome is named after Dutch paediatrician Cornelia Catharina de Lange, who described it.

It is often termed Bushy Syndrome and is also known as Amsterdam dwarfism. It is a genetic disorder that can lead to severe developmental anomalies. It affects the physical and intellectual development of a child. Exact incidence is unknown, but it is estimated at 1 in 10,000 to 30,000.

What causes Cornelia De Lange Syndrome?

The vast majority of cases are due to spontaneous genetic mutations. Common features include:

- Low birth weight (usually under 5 pounds/2.5 kilograms)
- Delayed growth and small stature
- Developmental delay
- Limb differences (missing limbs or portions of limbs)
- Small head size (microcephaly)
- Thick eyebrows, which typically meet at midline (synophrys)
- Long eyelashes
- Short upturned nose and thin downturned lips
- Long philtrum
- Excessive body hair
- Small hands and feet
- Small widely spaced teeth
- Low-set ears
- Hearing impairments
- Vision abnormalities (e.g., ptosis, nystagmus, high myopia, hypertropia)
- Partial joining of the second and third toes
- Incurved 5th fingers (clinodactyly)
- Gastroesophageal reflux
- Seizures
- Heart defects (e.g., pulmonary stenosis, VSD, ASD, coarctation of the aorta)
- Cleft palate
- Feeding problems
- Hypoplastic genitalia

Children with this syndrome are often found to have long eyelashes, bushy eyebrows and synophrys (joined eyebrows). Body hair can be excessive and affected individuals are often shorter than their immediate family members. They present a characteristic facial phenotype and is recognizable with the Facial Dysmorphology Novel Analysis (FDNA) technology.

CdLS can give rise to its own array of complexities. Children with CdLS often suffer from gastrointestinal tract difficulties, particularly gastroesophageal reflux. Vomiting, intermittent poor appetite, constipation, diarrhoea or gaseous distention are known to be a regularity in cases where the GI tract problems are acute. Symptoms may range from mild to severe.

CdLS may include behaviour problems, including self-stimulation, aggression, self-injury or strong preference to a structured routine. Many children with CdLS exhibit autistic-like behaviours.

For more information http://rarediseases.org or www.cafamily.org.uk

Cardiac problems in children and young people

Heart Disease in Children

Heart disease is difficult enough when it strikes adults, but it can be especially tragic in children.

There are many different types of heart problems that can affect children. They include congenital heart defects, viral infections that affect the heart, and even heart disease acquired later in childhood due to illnesses or genetic syndromes. The good news is that with advances in medicine and technology, many children with heart disease go on to live active, full lives.

Congenital Heart Disease

Congenital heart disease is a type of heart disease that children are born with, usually caused by heart defects that are present at birth. In fact, the most common heart conditions found in children are structural heart defects, which occur in roughly 8 of 1,000 live births. These usually involve a problem with the heart muscle or the heart valves, and include:

- heart valve conditions like a narrowing of the aortic valve, which restricts blood flow, or a mitral valve prolapse, where the mitral valve leaks
- defects in the wall that separates the left and right sides of the heart (the septum)

Other congenital heart defects that affect children include:

- Hypoplastic left heart syndrome (HLHS), where the left side of the heart is underdeveloped
- Holes in the heart, typically in the walls between the chambers and between major blood vessels leaving the heart; they include ventricular septal defects, atrial septal defects, and patent ductus ateriosus
- Tetralogy of Fallot, which is a combination of four defects, including a hole in the ventricular septum, a narrowed passage between the right ventricle, pulmonary artery, a thickened right side of the heart, and a displaced aorta

Congenital heart defects may have long-term effects on a child’s health. They’re usually treated with surgery, catheter procedures, medications, and in severe cases, heart transplants. Some children will require lifelong monitoring and treatment.

Atherosclerosis

Atherosclerosis is the term used to describe the build-up of fat and cholesterol-filled plaques inside the arteries. As the build-up increases, arteries become stiffened and narrowed, which increases the risk of blood clots and heart attacks. It typically takes many years for atherosclerosis to develop. It’s unusual for children or teenagers to suffer from it. However, obesity, diabetes, hypertension, and other health issues put children at higher risk. Doctors recommend screening for high cholesterol and high blood pressure in children who have risk factors like family history of heart disease or diabetes and are overweight or obese. Treatment typically involves lifestyle changes like increased exercise and dietary modifications.

Arrhythmias

An arrhythmia is an abnormal rhythm of the heart. This can cause the heart to pump less efficiently.

Many different types of arrhythmias may occur in children, including:
- a fast heart rate (tachycardia)
- a slow heart rate (bradycardia)
- long Q-T Syndrome (LQTS)
- Wolff-Parkinson-White syndrome (WPW syndrome)

Symptoms may include:
- weakness
- fatigue
- dizziness
- fainting
- difficulty feeding

Treatments depend on the type of arrhythmia and how it's affecting the child's health.

Eisenmenger Syndrome

Though not a type of heart disease specifically, this syndrome typically indicates a problem with the heart. Eisenmenger's is actually a collection of three symptoms, including:
- cyanosis, pale blue or grayish skin due to decreased oxygen in the blood
- pulmonary hypertension, high blood pressure in the blood vessels of the lungs
- polycythaemia, excess number of red blood cells

This syndrome may affect adolescents and adults with certain congenital heart defects that were repaired later in life or were never repaired. However, it can also occur in newborns born with pulmonary hypertension. Basically, Eisenmenger syndrome is a sign that the blood isn't flowing correctly from the left to the right side of the heart. Left untreated, it can cause blood clots, stroke, and kidney failure. Treatment usually depends on the symptoms and involves medications to decrease pulmonary hypertension, supplemental oxygen, and sometimes a removal of blood to reduce the excess number of circulating red blood cells (phlebotomy).

Kawasaki Disease

This is a rare disease that primarily affects children and can cause inflammation in the blood vessels in the hands, feet, mouth, lips, and throat. It also produces a fever and swelling in the lymph nodes. Researchers aren't sure yet what causes it. According to the American Heart Association (AHA), the illness is a major cause of heart conditions in as many as 1 in 5 children. Most are under the age of 5. Treatment depends on the extent of the disease, but is often prompt treatment with IV gamma globulin or aspirin. Corticosteroids can sometimes reduce future complications. Children who suffer from the disease often require lifelong follow-up appointments to keep an eye on heart health. For more information www.healthline.com

Cerebral Palsy

What is cerebral palsy?
Cerebral palsy, or CP, is a group of neurological conditions affecting movement and co-ordination because of problems with the brain and the body's nervous system. Symptoms of cerebral palsy include muscle stiffness, floppiness, weakness, uncontrolled body movements and problems with balance and co-ordination. Cerebral palsy is one of the most common causes of chronic childhood disability, affecting around one in every 400 people in the UK. Cerebral palsy usually appears in children before they are three years old. Although the brain damage doesn't worsen over a person's lifetime, symptoms can vary in their severity. Children with cerebral palsy may have an accompanying seizure disorder and may have some level of learning disability, vision, speech, hearing or language problems.

What causes cerebral palsy?
Causes of cerebral palsy include:

- Infections during pregnancy that may damage the nervous system of a developing foetus. These include rubella (German measles), cytomegalovirus (a herpes-type virus) and toxoplasmosis (an infection caused by a parasite that can be carried in cat faeces or undercooked meat).
- Other infections in pregnant women that may go undetected are now being recognised as important causes of developmental brain damage in the foetus.
- Severe jaundice in the baby. Jaundice is caused by excessive bilirubin in the blood. Normally, bilirubin is filtered out by the liver. But often a, newborn baby’s livers needs a few days to start doing this effectively, so it's not uncommon for babies to have jaundice for a few days after birth. In most cases, phototherapy (light therapy) clears up jaundice and there are no lasting health effects. However, in rare cases, severe untreated jaundice can damage brain cells.
- Rh (rhesus) incompatibility between mother and baby. With this blood condition, the mother's body produces antibodies that destroy the foetus's blood cells. This, in turn, leads to a form of jaundice in the baby and may cause brain damage.
- The physical and metabolic trauma of being born. This can precipitate brain damage in a foetus whose health has been threatened during development.
- Severe oxygen deprivation to the brain or significant trauma to the head during labour and delivery.

Some children with cerebral palsy acquire the disorder after birth. It results from brain damage in the first few months or years of life. Cerebral palsy often follows infections of the brain, such as bacterial meningitis or viral encephalitis, or it may be the result of a head injury.

What are the symptoms of cerebral palsy?
The symptoms of cerebral palsy (CP) can vary from slight clumsiness to extensive spasticity (uncontrolled contraction of muscles attached to the skeleton). Early signs usually appear before the age of three. Parents are often the first to suspect that their child’s motor skills are not developing normally or that their child is slow in developing. Often babies with CP are slow to reach developmental milestones such as learning to roll over, sit, crawl, smile or walk. Some affected children seem rigid or stiff. They also may exhibit an unusual posture or favour one side of their body.

There are four types of CP:

- Spastic CP, the most common type, is a disorder where certain muscles are stiff and weak. The stiffness can occur mainly in the legs (diplegia), only in the arm and leg of the same side (hemiplegia) or in both arms and legs (quadriplegia). A wide-based, staggering or "scissors" gait is characteristic of this type.
- Dyskinetic (or athetoid) CP generally involves impairment of voluntary muscle control. People with this form of CP have incomplete or fragmented motor movements often involving bizarre twisting motions, tremors and exaggerated posturing (athetosis).
- Mixed CP is a combination of the previous two types of CP.
- Ataxic CP can be the combination of uncoordinated movements, loss of power, hypotonia and tremor.

What treatment is there for cerebral palsy?
Cerebral palsy is a lifelong condition that cannot be cured. However, treatment can improve an affected person's capabilities, increasing motor function and independence. Many people who have CP enjoy near-normal lives. Depending on his or her symptoms, a person with CP may need the following:

- Surgery is used to correct muscle contractures, bending at a joint due to muscles that are too short or are spastic. With this surgery, muscle is lengthened. In another type of surgery, certain spinal nerves may be severed to help reduce spasticity in the legs.
- Medicines which treat muscle problems and other symptoms. Medicines such as diazepam, baclofen and dantrolene are sometimes used to control muscle spasticity. Anticholinergic medicines may be used to help control abnormal movements. Alcohol or Botox injections into muscle may be used to reduce spasticity for a short time so doctors can work to lengthen a muscle. Baclofen infused into the spinal canal under control of an electronic pump may be used to control spasticity for long periods of time. Other medicines may also be given to control seizures.
- Physiotherapy which consists of special exercises designed to increase and improve the child's movement and strength. In healthy children, normal daily activity stretches muscles, which helps the muscles to grow faster to keep up with the child's growing bones . However, the muscles of children with CP do not stretch and grow normally. As the child ages, the difference between bone growth and muscle growth can interfere with motor abilities. Physiotherapy helps combat this.
- Mechanical aids which may help with a wide variety of functions. These aids can range from orthotic braces that help stretch muscles by holding bones in certain positions, to a computer equipped with special input devices and a speech synthesiser to help the person communicate.
- Occupational therapy designed to help the child develop the fine motor skills needed to function day to day at home and school.
- Speech therapy to help the child overcome communication problems.
- Counselling to help the child and his or her family cope with the child's condition and access useful services.
- Specially designed educational programmes for those who have learning disabilities.

Reviews by an audiologist regarding hearing and an ophthalmologist regarding visual conditions may also be required. For more information www.scope.org.uk

Cancer in children and young people

Cancer in children and young people is rare. In the UK, only 1 in every 500 children under 15 develops a cancer. So about 1,600 children (up to the age of 15) in the UK are diagnosed with cancer each year. Children's cancers can be quite different from cancers affecting adults. They tend to occur in different parts of the body to adult cancers. They also look different under the microscope and respond differently to treatment. In the UK, around 2,200 teenagers and young adults (15-24 years old) are diagnosed with cancer every year. Cure rates for children are much higher than for most adult cancers. The survival rate for children’s cancer has more than doubled since the 1960s. On average, 82% (over 8 in 10) of all children can now be completely cured. For some types of children’s cancer, the cure rate is much higher.

Types of children’s cancer :

Leukaemia

Leukaemia is a cancer of the bone marrow. This is the spongy material in the middle of our bones where blood cells are made. When someone has leukaemia, their body produces too many abnormal white blood cells. The cells don’t usually form a lump (tumour), but travel around the body in the blood.

Leukaemia is the most common cancer in children. The main types found in children are:

- acute lymphoblastic leukaemia (ALL)
- acute myeloid leukaemia (AML).

Each type of leukaemia can be divided into different sub-types. Blood and bone marrow samples will be tested to find out which type of cell has become leukaemic and at what stage of its development this happened. The cells may be tested to see if they have certain proteins on their surface. This is known as immunophenotyping which aids the diagnosis.

Almost all of the cells in our body contain chromosomes. Chromosomes are made up of genes, which control the activity of the cell. There are often changes in the structure of the chromosomes in leukaemia cells. Testing the cells for these changes is known as cytogenetics. Knowing the exact type of leukaemia your child has helps the doctors plan the most effective treatment.

Sarcomas

Sarcomas develop from tissue such as bone or muscle, and can occur in any part of the body.

Embryonal tumours

These develop from tissue that is normally only seen in the developing embryo. They can also occur in different parts of the body.

Lymphoma

Lymphoma is cancer of the lymphatic system and can occur in any lymphatic tissue in the body. There are two main types of lymphoma: Hodgkin lymphoma (HL) (sometimes called Hodgkin’s disease) and non-Hodgkin lymphoma (NHL).

Neuroblastoma

Tumours of nerve tissue can occur in any part of the body.
Brain and spinal cord tumours may be benign (non-cancerous) or malignant. The symptoms experienced depends on the area of the brain in which the tumour lies

Teenagers and young people tend to get different types of cancers to children and adults with the most common ones being lymphomas and carcinomas, germ cell (ovarian and testicular) and brain and central nervous system (CNS) tumours.

The doctors will want to check that everything is well and ensure that your child doesn’t have any long-term problems following their cancer treatment.

Certain treatments can sometimes affect a child’s future development. The doctors will be able to discuss any specific long-term effects your child might have in more detail with you.

Some effects are as follows:

Puberty and fertility

Some treatments may affect your child’s puberty and fertility. These include:

- radiotherapy to the brain
- radiotherapy to the lower abdomen or pelvis (that includes the ovaries or testicles)
- total body irradiation (TBI), usually done with a bone marrow transplant
- some chemotherapy drugs
- surgery to the ovaries, womb or testicles.

Your child will be checked regularly for signs of puberty. If this appears to be delayed, hormone replacement therapy may be needed so that puberty can occur.

Understandably, it’s very distressing to think that your child may not be able to have children in the future. They may also find this difficult to cope with, either now or in the future, as they move towards adulthood. For children who have already reached puberty, it can be difficult to know whether or not cancer treatment has affected their fertility until they’re old enough to have hormone tests.

Growth and development

Radiotherapy can have an effect on a child’s growth and development. It may affect growing bones - for example, if radiotherapy is given to the spine, your child may not grow as tall as expected, or if radiotherapy is given to a leg, that leg may be shorter than the other.

The pituitary gland at the base of the brain produces hormones that help to regulate growth and development from childhood to adulthood. Radiotherapy to the brain may affect the production of growth hormone by the pituitary gland. If your child doesn’t produce enough of this, they will not grow normally and may need treatment with a man-made growth hormone.

Your child will be regularly weighed and measured at the follow-up clinics. If their growth has been affected, tests will be done to see if replacement growth hormone is needed.

Effects on the heart and lungs

Certain treatments can affect the heart and lungs. These treatments include some chemotherapy drugs and radiotherapy. The effects may not be seen for some time after treatment finishes. If your child is at risk of these problems, they'll be regularly followed up with echocardiograms (heart ultrasound scans). Sometimes, special tests on the lungs (lung function tests) are also needed.

Hearing loss

Hearing problems after cancer treatment are uncommon but they may occur with certain drugs and after radiotherapy to the head, in the region of the ear. Cisplatin is the drug most likely to cause hearing impairment (i.e. partial deafness). This causes particular difficulty in hearing high-pitched noises, and can be detected by sensitive hearing tests. It is seldom severe enough to be noticeable by either the patient, their family or friends, since the lower pitched noises used for speech are not usually affected.

Kidney problems

These can occur after some types of treatment for children's cancer, but fortunately they aren't usually severe. Removal of one kidney as part of treatment doesn't usually cause any problems because the remaining kidney can make up for the one removed.
Some chemotherapy drugs can cause kidney problems. If your child has had these drugs, their doctor will arrange tests, such as GFR, to check their kidneys from time to time. Children whose kidneys are working well at the end of treatment shouldn't develop problems in the future.

Intellectual development and education

Following treatment, most children are able to continue with normal education and the development of their ability to think and understand (intellectual development) is not affected. However, some children, especially children treated for brain tumours, may develop learning difficulties and need to have special help at school. Processing and short-term memory loss are the predominant factors, with some experiencing educational loss accrual as time progresses

The extent of these difficulties will depend on the age of your child when they were treated, and the treatment they had.

Some children will need a Child's Plan to provide the necessary help in the school environment. You can discuss this with your child's doctor who can give details of treatment and, if necessary, contact the school or education authority.

Second cancer

A very small number of children who are cured of cancer may develop a different cancer later on in life. There are two main reasons for this. Firstly, some families have an inherited risk factor for cancer, although this is rare. Also, some cancer treatments can themselves increase the risk of developing other cancers. For more information www.clicsargent.org.uk or www.teenagecancertrust.org.uk or http://www.macmillan.org.uk

Self-Harm

What is self-harm?
The phrase ‘self-harm’ is used to describe a wide range of behaviours. Self-harm is often understood to be a physical response to an emotional pain of some kind, and can be very addictive. Some of the things people do are quite well known, such as cutting, burning or pinching, but there are many, many ways to hurt yourself, including abusing drugs and alcohol or having an eating disorder. Sometimes, it’s more important to focus on how someone is feeling rather than what they do to themselves. Quite often, people find that more helpful.

Everyone has accidents from time to time resulting in cuts and bruises - but it's the injuries that are caused on purpose that are considered to be acts of self-harm. Self-harm often happens during times of anger, distress, fear, worry, depression or low self-esteem in order to manage or control negative feelings. Self-harm can also be used as a form of self-punishment for something someone has done, thinks they have done, are told by someone else that they have done, or that they have allowed to be done to themselves.

People often ask if what someone is doing to themselves can be classified as self-harm. The bottom line is that anything that causes you harm – even slight harm – which in some small way makes you feel better emotionally, can fall under the umbrella of self-harm. The important thing isn’t to focus too much on the labelling, but to recognise when help is needed and find some support as soon as possible.

Sometimes, self-harm is referred to as self-injury. It doesn’t matter which term you use, providing you feel you are being heard and understood.

Who self-harms?
Self-harm affects people of all ages and from all walks of life – regardless of where someone is from, what their social or cultural background might be, or how well they perform at school. You are not necessarily more likely to have a problem with self-harm if you come from a more deprived part of town; it doesn’t matter if your parents are together or divorced, if you come from a single parent family or if your parents are employed or not. Young people growing up in care are not more or less likely to self-harm than teenagers who live with their families. It really can, and does, affect anyone.

It is thought that around 13% of young people aged 11-16 will self-harm at some point. Research suggests that children exposed to others’ self-harm may be more likely to begin harming themselves, so it’s important that siblings and friends receive support to understand self-harm as much as the person affected.

The important fact to remember is that you will not be alone in this; you will not be the only one struggling, nor will you be the only person with a friend, brother, sister, child or pupil who self-harms. There may be lots of people in the same situation as you, so don’t ever feel alone.

What makes people start harming?
The thing that triggers someone to self-harm for the first time will be different for each person. It could be a reaction to an argument, or a situation that has left someone feeling rejected, humiliated, depressed or angry. Equally there will be many more young people

who experience the same emotions and do not hurt themselves; harming is a method of coping with difficult emotions and different people cope in different ways. One young person may cope with a bad grade at school by watching television and forgetting about it, another may play computer games, listen to music or study harder, whereas others may hurt themselves. Some people injure themselves because friends are also doing it and consider it to be ‘cool’, or view it as a sign of someone’s commitment to a gang. It will be individual and unique to each person.

Not everyone who harms will go on to struggle for many years; for some it may only happen once or twice or just during a period of exceptional stress such as exams or moving house.

Why people self-harm

People harm themselves for all sorts of reasons. The need to self-harm usually comes from emotions that have become difficult to manage, although sometimes it may be a sign of an underlying mental health issue.

Self-harm is a personal response, and it doesn't resolve any difficult emotions in either the short or long term. People often find that the immediate relief self-harm seems to bring is usually quickly replaced by an even greater sense of distress. It is only through talking about and understanding the emotions involved, that the need to self-harm can be reduced and eventually taken away.

Why people continue to self-harm after others have found out

Self-harm doesn’t automatically stop when you confront or acknowledge it. Seeing friends and relatives upset at finding out can make it even harder for someone to stop; the guilt can push them to harm even more as a way of coping with other people’s emotions. The fear of further being found out can push the self-harming underground, making it even more secretive and therefore difficult to treat or offer help and support. This highlights the need for disclosures to be handled sensitively. Just telling someone to stop won’t work.

Some people find the process of self-harm to be very addictive; the act of harming causes the body to produce endorphins, which can produce a feeling similar to an adrenaline rush. The rush lessens as time goes on so the acts of self-harm get bigger and more damaging in order to achieve the same sensation. It’s the same response people have to drug taking – more is needed to get the same ‘hit’. It's a very dangerous cycle to fall into.

Some people don’t find harming addictive in a physical sense but may become dependent on it emotionally. Harming may hold back unwanted feelings, so it may become a habit and part of a daily routine to reduce the risk of those feelings popping up in the first place – prevention rather than cure. Giving up harming means these feelings may surface, and that can be a frightening prospect. This is why it is important for people to have the chance to talk about how they feel, and to learn new ways of coping.

Useful websites for parents

www.handsonscotland.co.uk
www.youngminds.org.uk
www.mentalhealth.org.uk
www.rcpsych.ac.uk/healthadvice/parentsandyouthinfo.aspx

www.winstonswish.org.uk - specific information for professionals, parents, and young people on bereavement.

All of the above sites are available on Facebook and Twitter.

Useful websites for young people
www.handsonscotland.co.uk
www.youngminds.org.uk
www.mentalhealth.org.uk
www.rcpsych.ac.uk/healthadvice/parentsandyouthinfo.aspx
www.childline.org.uk
www.winstonswish.org.uk - specific information for professionals, parents, and young people on bereavement.

All of the above sites are available on Facebook and Twitter.

Useful websites for professionals
www.handsonscotland.co.uk
www.youngminds.org.uk
www.mentalhealth.org.uk
www.rcpsych.ac.uk/healthadvice/parentsandyouthinfo.aspx
www.winstonswish.org.uk - specific information for professionals, parents, and young people on bereavement.

All of the above sites are also on Facebook and Twitter

Suicide

Manchester University Centre for Mental Health Safety.

The Centre for Mental Health and Safety is an internationally recognised Centre for research into suicide, homicide and self-harm within the general population and within groups known to be at higher risk of these outcomes. The Centre is also home to research into the impact of mental illness on families and the experience of those bereaved by suicide. Their findings have shaped the development of national policy and had wide-ranging impact on professional practice in health and social care settings.
http://research.bmh.manchester.ac.uk/cmhs/research/

Why do some people take their own life?

There's no single reason why someone may try to take their own life, but certain things can increase the risk.

A person may be more likely to have suicidal thoughts if they have a mental health condition, such as depression, bipolar disorder or schizophrenia. Misusing alcohol or drugs and having poor job security can also make a person more vulnerable.

It's not always possible to prevent suicidal thoughts, but keeping your mind healthy with regular exercise, healthy eating and maintaining friendships can help you cope better with stressful or upsetting situations.

Why people attempt suicide

Despite being a leading cause of death, both in the UK and worldwide, there is little hard evidence to explain why some people attempt suicide.

Most people who choose to end their lives do so for complex reasons. In the UK, research has shown many people who die by suicide have a mental illness, most commonly depression or an alcohol problem.

In many cases, suicide is also linked to feelings of hopelessness and worthlessness.

Vulnerability to suicide

Many experts believe a number of things determine how vulnerable a person is to suicidal thinking and behaviour. These include:

- life history – for example, having a traumatic experience during childhood, a history of sexual or physical abuse, or a history of parental neglect
- mental health – for example, developing a serious mental health condition, such as schizophrenia
- lifestyle – for example, if you misuse drugs or misuse alcohol
- employment – such as poor job security, low levels of job satisfaction or being unemployed
- relationships – being socially isolated, being a victim of bullying or having few close relationships
- genetics and family history

In addition, a stressful event may push a person "over the edge", leading to suicidal thinking and behaviour.

It may only take a minor event, such as having an argument with a partner. Or it may take one or more stressful or upsetting events before a person feels suicidal, such as the break-up of a significant relationship, a partner dying or being diagnosed with a terminal illness.

Mental health conditions

It's estimated 90% of people who attempt or die by suicide have one or more mental health conditions(2012). However, in some cases, the condition may not have been formally diagnosed by a clinician. Conditions leading to the biggest risk of suicide are described below.

Severe depression

Severe depression causes symptoms of low mood, tiredness, loss of interest, despair and hopelessness that interfere with a person's life. People with severe depression are much more likely to attempt suicide than the general population.

Bipolar disorder

Bipolar disorder causes a person's mood to swing from feeling very high and happy to feeling very low and depressed. About one in three people with bipolar disorder will attempt suicide at least once. People with bipolar disorder are 20 times more likely to attempt suicide than the general population.

Schizophrenia

Schizophrenia is a long-term mental health condition that typically causes hallucinations (seeing or hearing things that are not real), delusions (believing in things that are not true) and changes in behaviour. It's estimated that one in 20 people with schizophrenia will take their own life.

People with schizophrenia are most at risk of suicide when their symptoms first begin. This is because they frequently suffer loss at this time – for example, loss of employment and relationships. It's also increased when people with schizophrenia experience depression. The risk tends to reduce over time.

People with schizophrenia are also at increased risk of self-harm.

Borderline personality disorder

Borderline personality disorder is characterised by unstable emotions, disturbed thinking patterns, impulsive behaviour and intense but unstable relationships with other people. People with a borderline personality disorder often have a history of childhood sexual abuse. They have a particularly high risk of suicide.

Self-harm is often a key symptom of this condition.

It's estimated just over half of people with borderline personality disorder will make at least one suicide attempt.

Anorexia nervosa

Anorexia nervosa is an eating disorder. People with anorexia feel fat and try to keep their weight as low as possible. They do this by strictly controlling and limiting what they eat, as well as sometimes inducing vomiting. It's estimated around one in five people with anorexia will make at least one suicide attempt. Anorexia is associated with a high risk of suicide.

Other risk factors for suicide

Other things that can make a person more vulnerable to suicidal thoughts include:

- prejudice experienced because of being gay, lesbian or transgender.
- being in debt
- being homeless
- being a war veteran
- being in prison or recently released from prison
- working in an occupation that provides access to potential ways of dying by suicide, such as working as a doctor, nurse, pharmacist, farmer or as a member of the armed forces
- exposure to other people with suicidal behaviour, especially close friends or family members

Antidepressants and suicide risk
Some people experience suicidal thoughts when they first take antidepressants. Young people under 25 seem particularly at risk.

Contact your GP immediately or go to your local hospital if you have thoughts of killing or harming yourself at any time while taking antidepressants.

It may be useful to tell a relative or close friend if you have started taking antidepressants. Ask them to read the leaflet that comes with your medication. Also ask them to tell you if they think your symptoms are getting worse or if they are worried about changes in your behaviour.

Genetics and suicide
Suicide and some mental health problems can run in families. This has led to speculation that certain genes may be associated with suicide.

However, it would be too simple to claim there's a "suicide gene" as the factors leading to suicide are complex and wide ranging. Genetics may influence personality factors (such as acting impulsively or aggressively) that may increase the risk of suicidal behaviour, especially when a person is depressed.

Other theories
An American psychologist called Thomas Joiner developed a theory known as the interpersonal theory of suicide. The theory states three main factors which can cause someone to turn to suicide. They are:

- a perception (usually mistaken) they are alone in the world and no one really cares about them
- a feeling (again, usually mistaken) they are a burden on others and people would be better off if they were dead
- fearlessness towards pain and death

The theory argues fearlessness towards pain and self-harm may be learnt over time, which could explain the strong association between self-harming behaviour and suicide.

People who are regularly exposed to the suffering and pain of others may develop this fearlessness over time. This could help explain why suicide rates are higher in occupations linked to such exposure, such as soldiers, nurses and doctors.

How common is suicide?
During 2012 there were 5,981 suicides in the UK but the number of attempted suicides is much higher.

Suicide occurs in people of all ages, including children, but adults in middle- and late-middle age have the highest suicide rate.

Sudden Unexpected Death

There are a large number of reasons why a death may occur suddenly, a car accident for example.

There is however a syndrome called Sudden Death Syndrome which might be involved in a family experiencing unexpected loss.

What is Sudden Death Syndrome?
Sudden death syndrome describes a sudden, unexpected death which may occur during sleep, whilst awake, or just after exercise. Most sudden deaths are due to a heart condition and are known as sudden arrhythmia death or sudden cardiac death syndrome.

Sudden arrhythmia death is most commonly due to a serious abnormal change to the heart's rhythm known as an arrhythmia, such as ventricular tachycardia.

Sudden cardiac death describes a sudden death as a result of an un-resuscitated cardiac arrest or heart attack.

Who is at risk of sudden death syndrome?
Sudden death syndrome can occur to anyone.

What causes sudden death syndrome?
There are a number of heart conditions that can cause sudden death syndrome however the cause of sudden death can often remain unknown until a post-mortem has been performed. The majority of victims have no warning signs or prior symptoms.

What can be done to prevent sudden death syndrome?
The majority of sudden deaths are due to inherited heart conditions. Screening family members where there has been a heart condition or a previous sudden death, including a sudden infant death (SIDS), could identify pre-existing conditions that may cause sudden death. Appropriate treatment could then prevent or reduce the risk of sudden death occurring.

What can be done to prevent sudden death syndrome?
The majority of sudden deaths are due to inherited heart conditions. Screening family members where there has been a heart condition or a previous sudden death, including a sudden infant death (SIDS/cot death), could identify pre-existing conditions that may cause sudden death. Appropriate treatment could then prevent or reduce the risk of sudden death occurring.

Sudden Unexpected Death in Infancy (Cot Death) and Neo-natal Death

Many organisations play a role in investigating SUDI. Although the terminology SUDI is only used for children up to the age of two years, and therefore not of school age, Schools should be aware of the impact on the siblings and family of an infant that has died. The death of a close family member is considered to be an Additional Support Need under the ASN Act 2010, and Schools should be actively supporting pupils affected in this way.

The SUDI toolkit offers a support resource, including suggestions on how to support the bereaved families. Professionals can download, print or email resources from individual guidance, or use the interactive timelines which demonstrate how professionals interact during an investigation.

When an infant dies, either at home or after a new born baby has been discharged from hospital, the death has to be investigated. The death is investigated initially by the Police. The Police try to show a balance of sympathy and understanding, but the place of death has to be treated as a potential crime scene.

Infant deaths are rare in the North of Scotland. There is a centralised Procurator Fiscal system to deal with them so any death is dealt with by an experienced team.

Investigations take place for:
- Any SUDI
- Any death of a newborn found
- Death of a Looked After Child
- Death of an infant from suffocation

SUDI – this term is only used if no cause of death can be found, or there are some causes which may have contributed to the death, but cannot be the sole cause.

Support for families
The investigation process can be lengthy, microbiological investigations can take 4-6 months to reveal results. The Family, as well as dealing with the loss of a child, may be under further stress from going through this difficult process.

The SUDI process is designed to ensure that the professionals involved highlight the support available to the families, either from a Family Liaison Officer or from the Cot Death Trust. It is vital that parents are offered this information from several sources as they may not take in the information, or be ready to access it, initially.
Further information can be found at **www.sudiscotland.org.uk**

The Scottish Cot Death Trust

Main Aims:
- To fund research into cause/causes
- To improve support to families
- To educate professionals and the public about Cot Death

The ‘Back to Sleep’ campaign has greatly reduced the number of baby deaths. However, a strong link between Cot Death and family deprivation has been made. Babies are at greater risk in homes where there is alcohol/drug misuse and in homes where parents smoke or have smoked during the pregnancy. Infants sleeping with a parent on a bed, sofa or chair are at an increased risk of Cot Death.

The Cot Death Trust can provide useful support materials for a School dealing with a family which has suffered a Sudden Infant Death, including a book called ‘Rory’s Star’ which is a resource for siblings.

Secondary Schools can play an important role in promoting knowledge to students about the causes of Sudden Infant Death. The Cot Death Trust can provide information for Schools to use in PSE (Health and Wellbeing) including:
- Reduce the Risk leaflets
- Teaching programme
- Smoking reduction in pregnancy campaign

Further information can be found at http://www.scottishcotdeathtrust.org/

Bereavement in the School

We all grieve for unwelcome change in our lives, whether through failed job interviews, exams, dissolved relationships or the death of something close to us – animal or human. The way we grieve is proportionate to the significance of that loss, none more so than the death of a child or sibling, or in the case of children, the death of their parent. However bereavement is a normal process of healing and should not be 'medicalised' through the seeking of professional help for the bereaved person unless there are signs of complicated grief and persistent evidence of non-coping. There is no 'cure' and the focus should not be an attempt to 'fix' the situation. This does not mean that we cannot listen and be available to support people through that process which may, if very significant, take a number of years to get to a place of allowing grief thinking not to be dominant. Remember, children's grief will also include that related to still birth, neonatal or sudden infant death syndrome (formerly known as cot death) of a sibling.

Terms in which the death should be explained
In explaining death to children, it is important always to be honest and consistent, without giving details which are unnecessary or disturbing. The cause of natural death can be explained by saying that the deceased 'was very old so that his body wore out or that an illness where the body stopped working' and could not be made better'. Care should be taken, when mentioning illness, to prevent the child being concerned about going to the doctor in the future.

A simple, factual description of death is recommended both for children and for those with learning disabilities. There should be no suggestion that there is hope of return, and euphemisms such as 'gone to sleep', 'left us', or 'you have lost your father/mother', should be avoided as they lead to confusion.

Are dead people sleeping? A clear distinction should be made between sleep and death. Sleep gives rest and renewal. Death is when the body stops working.

What happens to dead people? Our bodies wear out, that the dead person cannot have feelings, cannot feel hot or cold, hurt or sick. A simple explanation is then given of cremation and burial.

The grieving process
Most adult grief moves between a solution-focused behaviour where the person's energy is more practically orientated, and an emotion-focused behaviour where thinking relates to feelings (Strobe and Schut model). Whilst disbelief or numbness, guilt, bargaining, anger and resolution (Kubler-Ross) is recognised, the experience is much more fluid and will oscillate across the range on any given day. Coping reflects this. It is worth noting that there may well be disparity between men and women in their coping strategies that can lead to arguments and resentment. The 'strength' of coping at any one time between parents is often shared swinging from one to another as the partner's coping changes. The way that people grieve is not a measure of the intensity of grief being experienced.

The volume of grief does not change but the space available to get on with living grows around that grief. However the timescales for this 'resolution' may take many, many years, particularly with the death of a child.

Culture and Grief

Our experiences of life and death influence our grieving. Some children and their siblings will have been exposed to situations in hospital where they have formed friendships or who have knowledge of children who have died. They may have had conversations about their own life expectancy. This means their understanding is greater than that of the average child at that age. Children's grief will also be influenced by witnessing their parents' grief. Culture, ethnicity, religion and belief systems influence acceptance of death, including beliefs about where their loved one has gone. Beliefs are individual, and understanding the cultural background to this is key to supporting the child. Cultural/religious beliefs expressed by the child should never be contradicted by professionals even if they are in conflict with our own. See multi-faith resource for Healthcare staff for guidance: www.nes.scot.nhs.uk/education-and-training (spiritual care)

Risks for children

Around 4% children under 16 years are bereaved of a parent or sibling each year.
67% children excluded from school had experienced death of parent or sibling.

40% prison inmates bereaved in childhood (Winston's Wish) www.winstonswish.org.uk

Children's grief resilience is closely connected to parent coping. There is a higher risk of grieving disparity between parents, higher risk of 'complicated grief', higher risk of relationship break up, and higher risk of drugs/alcohol abuse. This means that children may well be living in a background of chaos and potentially emotional or physical violence in the home. School staff need to be aware of, and raise safe-guarding concerns if there is any evidence of this.

How do children grieve?

Understanding of death changes over time so that many will need to revisit and re-frame that grief as they mature. The re-visiting of that grief is often triggered by significant events.

0-3 years – Separation anxiety. Cued in to emotional environment. Angry / tearful outbursts. Looking for deceased. Children in later life, may need help to create memories of the person they did not get to know

3-5 years – Need support to understand what 'dead' means – use of animal analogies useful. Avoid euphemisms. 'Magical thinking'. Rapidly dip in and out of grief.

5-8 years – Compare with peers, issues with boundaries and challenging power dynamics. Clear and consistent routines, boundaries and expectations of behaviour required. Death is fascinating so may ask many questions, particularly about ‘ God’. May worry about death of self and others.

9-12 years – More mature understanding of permanency and focus on how the death will continue to affect them. May demonstrate feelings of guilt.

13-18 years – May be preoccupied with the meaning of life and death. Relate loss to future events. May exhibit risk-taking behaviours and challenge authority. May under achieve or excel beyond expectation academically. Drive for independence yet strong desire to feel they belong. Often teenagers and parents mutually protect each other to avoid having to deal with emotions such that teenagers choose an alternative ‘safe’ person to talk to.

Signs of grief
Physical- aches, lump in throat, headache, abdominal pain, tight chest, no energy, mimic deceased’s symptoms.
Social- poor social interaction, poor school attendance, low-self-esteem, worry about self or others.
Behavioural- sleep difficulty, loss of appetite, poor concentration, forgetful, withdrawal, dreaming, crying, aggressive/passive, over focus on work or activity, cherishing places/objects.
Feelings – like you’re outside of yourself, anger, guilt, loneliness, anxiety, yearning, shock, relief, freedom, anxiety, confusion.

How school staff can help
- School is a place of normality. Staff should agree with the child as to how much information can be given out to other staff or pupils.
- Identify a key person with whom the child/young person has trust.
- Show empathy. The demonstration of caring v. apparent non-caring can help or hinder more than the content of the conversation.
- Be available – offer a set time each week, but also open availability.
- Allow free talk rather than forced conversation.
- Use open- ended questions that do not require a ‘yes/no’ response.
- Be aware that conversations will start slowly and build. Don’t try to cover too much at a time.
- Be honest with answers, and be conscious there may be no answers.
- Be conscious of material in story writing and relevance to grief.
- Work with the family so that messages are not contradictory and that family beliefs and values are respected.
- ‘Get out of jail card’ if child feels overwhelmed and needs to exit from class urgently (pre-arranged place and person to go to).
- Use of poems, songs, writing activity may help with non-verbal expression.
- Be conscious of allocated workload and capacity of child to focus. May need time extensions. Without drawing attention, the child may need gentle re-focus from ‘dreaming’ in classroom.

When to seek extra help
Do not assume necessarily that behaviours are linked to bereavement as there are many other factors that may confound this that may occur in others within the school population:
- Prolonged grief behaviours

- Aggression/violence
- Alcohol or drug use
- Self-harm or suicidal thoughts
- Repeated poor attendance at school (including late starts)
- Extreme fatigue
- Concerning reports directly or indirectly

Children with Learning Difficulties or Autism
It is absolutely essential that those offering support to a bereaved child have not only a good general understanding of their learning disability/autism, but they must also know the pupil/student well and be skilled in observing and interpreting both their verbal and non-verbal reactions. The grieving process of people with LD/autism is impeded by their disabilities of communication, and social interaction and difficulties of cognition. Because people with learning difficulties are restricted in their social interactions, it might be concluded that they do not form attachments to other people, and are therefore insulated from the grieving process. In fact they can be deeply affected by the death of someone close. All people react individually to bereavement but children with learning difficulty may share the ‘common reactions to bereavement’.

The grieving processes of people are profoundly affected by their disabilities. This is especially so for young people with autism. It is likely that many people with learning difficulties will share the difficulty children with normal intelligence under the age of 10 have in grasping all three of the aspects of death, - that it is inevitable, irreversible, and universal.

Young people with learning difficulties can have bizarre and distorted ideas of death. If staff detect misunderstandings about death in a young person, they should try to clarify their source and nature by sensitive questioning and observation, in order to tackle them effectively. Working in partnership with parents to recognise the child’s expression of grief through behaviour changes at home or school will enable staff to better gauge the support required.

Failure to grieve after loss
Some people with autism and others with learning disabilities do not grieve after loss. These few examples do not justify an assumption that they do not have a capacity to feel emotion or that if an individual does not exhibit grief in an expected way that does not mean that they are not grieving. No reaction to one bereavement does not mean there will be no reactions to subsequent bereavements. Grief is often a delayed process for people with learning disabilities. They fail initially to understand the implications of their loss, but may come to feel the impact many months or years later.

It is normal in the early stages of bereavement to behave as though the deceased still lives or even is present, and to experience difficulty in accepting the finality of death. It may be that the pupil/student’s repeated questions about the return of the deceased after the funeral and burial or cremation are a way of coming to terms with their loss. They may feel a need to check the consistency of the replies they are given or their questions may be their way of showing that they need comfort and reassurance.

Uncertain and inappropriate responses to bereavement
There have been a number of examples of people with autism who have expressed uncertainty regarding how they should react to death: ‘Should I feel sad?’; ‘How sad should I feel?’; ‘Shall I cry?’. Others have reacted by giggling at the funeral or at the

gravesite – perhaps a reflection of this uncertainty. This is also a reaction in young children. Some apparently uncaring comments can be the result of difficulties with verbal expression.

Because of communication difficulties, the only way a bereaved person with LD/autism may be able to express their grief is by disruptive or aggressive behaviour. It is difficult for staff to discover whether this arises from fear, anger or guilt or physical discomfort, all of which can accompany bereavement, or whether it arises from factors altogether unrelated to bereavement. Staff may need to intervene if undesirable habits or obsessions are introduced by the bereaved during their grieving process as a source of comfort, as these may persist long after the period of grieving.

Limited means of expressing grief

Grief counselling and listening therapeutic strategies are unavailable to most people with LD/autism unless staff can enable them to discuss their thoughts and feelings by sensitive questioning and by supplying appropriate words, signs or pictures. Because of the demands it makes upon them, this kind of attention may be unwelcome to the bereaved, who may find it threatening. On the other hand, unexpressed grief may go on at an unconscious level, which may precipitate symptoms of unresolved grief, such as deep depression. Because of their disabilities of social interaction, people with LD/autism are unlikely to seek support when they are anxious, depressed or unhappy and may require help in order to do so. People with autism are unlikely to have an expectation that the pain and suffering which they are experiencing will eventually come to an end. They therefore lack yet another possible source of comfort.

Limited number of relationships

The person with LD/autism has a very limited number of close relationships. Consequently, there may be a very substantial emotional investment in these, with the result that when they are terminated by departure or death the effect on the person may be catastrophic. They may also find it difficult to perform one of the tasks of grieving which is to effect an emotional withdrawal from the deceased and reinvest it in other relationships.

Sources of support

See suggested bereavement websites
See suggested bereavement booklist
Referral to Crocus child bereavement group (Highland)
Referral to Educational Psychology/CAMHS

Memory making ideas for schools

Many schools have found it very beneficial to make memories to help staff, pupils and families:

“What has really helped us as a department though was making a book of memories for the families where we were able to share photos and memories and write individual postcards to say what the young person meant to us. These were passed to the families who really appreciated them but before we did that we photocopied them and I know staff have really appreciated being able to go back into the memory book and to see the photos and read the messages. We keep the copies of the books in a quiet accessible place where staff can have a look. We also talk about the pupils with the rest of our pupils and keep the memories going.
This I think has helped us enormously as a department to deal with the deaths.”

‘Scrapbook’

- each child given 2 sheets of coloured 4”x4” paper – write down a memory or story (duplicate)
- photos of school events
- open to all pupils and teachers ? open up to local community
- original to family, 2nd kept in school
- Video / photo roll on school screen in hall/vestibule for a period of time
- Special service of celebration in school soon after death – perhaps pupils make biscuits cake to make it more relaxing and involves pupils
- Include mention of deceased child in future events e.g. award ceremonies - ? posthumous award to child, ? set up an e.g. ‘courage’ award in child’s name for other children to earn, remember child at Christmas time
- Invite parents back (with support) for these type of events
- Making a memory garden, memory bench/statue, herb garden
- Small stone painting / artwork constructed by pupils to display
- Balloon with message release (check L.A. restrictions on this)
- Making memory jars for pupils to take home (coloured sand representing a thought or feeling about child)

Additionally for children with learning disability
Retain a place in classroom for deceased child – chair or usual space
Encourage talking about deceased child in story telling but reinforce absence now
Photo of child, item of child’s personal belonging for pupils to touch/hold

http://www.sad.scot.nhs.uk

Looked after Children

Children in care may well have experienced a history of physical, emotional or sexual abuse, the death of a parent, have parents that cannot look after them because of illness or because of crimes they have committed, have severe disability or complex care needs. It is worth considering the following:

Additional losses

- Many of which may be repeated with each change of placement.
- Separated from their birth families – parents – siblings, and extended family.
- Change of schools and familiar environment.
- Loss of home, friends, pets, toys and shared possessions.

Additional attachment issues:

- May not have experienced close loving relationships impairing ability to feel secure and to grow and develop.
- Intense distress following separation from main carer.
- Ambivalent feelings towards foster parents/carers as protection.
- Early unmet attachment needs leading to difficulty in trusting that their future needs will be met.

Additional complications:

- Infrequent /disrupted contact.
- Hearing the news in a way that is difficult for them.
- Isolated from the rest of the grieving family, with anxiety for relatives they don't see
- The deceased may have been abusive or neglectful leaving a conflict between guilt/anger/grief.
- Carers may not be aware of the full details of a death or past losses.
- The looked after and bereaved child may be placed in an environment with peers who have a lesser capacity to be able to safely support them because of their own challenges and behaviours.
- Looked after children may have difficulty expressing their emotions. This may result in emotional/ behavioural challenges affecting their ability to form healthy and trusting relationships.
- There may be under-expression through withdrawal, self-harm or abuse of body, or conversely over-expression through aggressive or violent behaviours.

All of the previous information surrounding the understanding of death and support that children and young people require is relevant, however this situation reinforces the need for identification and availability of a consistent supportive adult. Care and Learning should use the Child's Plan process to establish a lead for each child with clear pathways of communication. Priority for long-term placements should be considered wherever possible.

Communicating the death of a child/young person or member of school staff

It is very important to acknowledge and recognise the emotional impact on the whole school community of a death of one of its pupils or staff members. No matter how prepared, or how well we know the child or staff member, the way in which the immediate family would wish that communication to take place will be extremely varied, influenced by their grief, their wishes for openness or privacy, and whether conversations have already taken place about this as part of planning. Balancing a need to sensitively communicate to the school community to prevent hearing distorted, inaccurate or potentially disturbing information via 'the grapevine' against privacy wishes can be challenging, but equally may result in anger from the family. Every situation is different and non-transferable but the following guidance may be helpful.

- Alert the Area Care and Learning Manager immediately of any expected or sudden death and involve the liaison Educational Psychologist and Primary Mental Health Worker as appropriate to support the school community.
- Establish a school protocol on ways of 'breaking bad news' – 1:1, small groups, staff meeting, school assembly
- In the event of an anticipated death of a child or young person with palliative needs – find out who is the Lead Professional (usually Children's Community Nurse, Children's Nurse Specialist or SW) and ensure contact numbers are recorded
- Identify a SINGLE person from the school to act as the lead in liaising with the family and communicating with outside agencies.
- In the event of an anticipated death, try and find out the wishes of the parent in communicating this news, as part of the proactive planning ahead of the event
- Whether sudden or expected, attempt to explore the views of the family either directly or in the case of a child, via the Lead Professional. The views of the family/parents, including any request for privacy should be respected. They may have specific requests on communication with:

    Teaching staff/PSAs/social carer staff
    Other parents
    Pupils
    Child's school and schools of siblings

  It would be helpful to share with them the HTs plan for the school community and gain their agreement with this, even if they don't have a strong view either way.
- Ensure the content of the news is factual, without including any distressing detail
- Ensure opportunities are given for pupils to speak to staff and for staff to speak with support services, where required.
- Look at ways of positive memory making
- Ensure all school staff are aware of strict codes of conduct re data protection, confidentiality and use of social media
- Ensure staff are aware of Highland Council's Communication team for management of press interest
- Ensure any letters that are sent out are on headed notepaper.

Bereavement Booklist

For parents or professionals

A multi-faith resource for healthcare staff (http://www.nes.scot.nhs.uk/education-and-training/by-discipline/spiritual-care/about-spiritual-care/publications/a-multi-faith-resource-for-healthcare-staff.aspx)

Helping children cope with separation and loss (Claudia Jewitt 1994) Advice for parents and professionals. Covers death, divorce, illness, and other challenges.

Seasons for growth – resource handbook for site coordinator (Programmes of work with children. www.goodgrief.aust.com)

PAMIS Bereavement and loss learning pack – for those supporting bereaved people with profound and multiple learning disabilities. (www.pamis.org.uk)

SeeSaw Hand-in-hand – supporting children and young people who have a learning difficulty through the experience of bereavement (www.seesaw.org.uk)

Poems and readings for funerals (Julia Watson 2004)

Coping with the impossible In our own words – Parents talk about life after their child has died of cancer. (Lois Tonkin via www.clicsargent.org.uk)

A child's grief – supporting a child when someone in their family has died (Di Stubbs) Winston's Wish

Helping your grandchildren when your child has died (Compassionate friends)

When your grandchild dies (Compassionate friends)

An intimate loneliness: supporting bereaved parents and siblings (Gordon Riches, Pam Dawson 2000) – how family members come to terms with the death of a child. An Intimate Loneliness explores how family members attempt to come to terms with the death of an offspring or brother or sister. Drawing on relevant research and the authors' own experience of working with bereaved parents and siblings, this book examines the importance of social relationships in helping parents and siblings adjust to their bereavement. The chances of making sense of this most distressing loss are influenced by the resilience of the family's surviving relationships, by the availability of wider support networks and by the cultural resources that inform each's perception of death. This book considers the impact of bereavement on self and family identity.

Whole schools approach to bereavement and loss (Glasgow) www.goodlifedeathgrief.org.uk

'A Girl Named Dennis' subtitled 'Finding a way through losing a child – a father's story.' (Matt Cunningham 2015) Written from the father's point of view and peppered with dark humour, this beautiful heart-rending memoir, part love story, part cry of pain, lays bare what it really feels like to love against the clock, to be a dad, a husband, a man out of his depth in the ultimate family crisis.

For children in preparation for dying

Gentle willow: a story for children about dying (Joyce Mills 2003) – **5s+**
Written for children who may not survive their illness or for the children who know them, the second edition of this tender and touching tale helps address feelings of disbelief, anger, and sadness, along with love and compassion.

Ways to Live Forever (Sally Nicholls 2015) – **10s+**
Sam loves facts. He wants to know about UFOs and horror movies and airships and ghosts and scientists, and how it feels to kiss a girl. And because he has leukaemia he wants to know the facts about dying. Sam needs answers to the questions nobody will answer. WAYS TO LIVE FOREVER is the first novel from an extraordinarily talented young writer. Funny and honest, it is one of the most powerful and uplifting books you will ever read.

A Monster Calls (Patrick Ness 2015) – **10s+**
Conor has the same dream every night, ever since his mother first fell ill, ever since she started the treatments that don't quite seem to be working. But tonight is different. Tonight, when he wakes, there's a visitor at his window. It's ancient, elemental, a force of nature. And it wants the most dangerous thing of all from Conor. It wants the truth. Bestselling novelist Patrick Ness takes the final idea of the late, award-winning writer Siobhan Dowd and weaves a heart-breaking tale of mischief, healing and above all, the courage it takes to survive.

For children in bereavement

Under 5s

Muddles, puddles and sunshine – interactive workbook (Diana Crossley 2000) Used with a supportive adult this is a useful resource, which when completed will be a wonderful memento that will help the grieving process. --Journal of the National Association of Hospital Play Staff

When uncle Bob died (Althea Happy Cat books 2001) When someone special dies a child may need to talk about them and share their feelings of confusion and sadness. When Uncle Bob Died offers a starting point for discussing death and their own thoughts about it.

Is Daddy Coming Back in a Minute?: Explaining Sudden Death to Pre-School Children in Words They Can Understand (Elke Barber 2012)
This book explains (sudden) death to very young children in a way they can understand for their age and stage of development. It is based on a true story, written by a parent after her 34 year old husband died very suddenly and unexpectedly and the conversations she had with her young son

Waterbugs and dragonflies – explaining death to children (Doris Stickney 2004) This book uses the analogy of the waterbugs' short life under water as human's time on earth and their emergence as dragonflies into the bright sunlit world above the water as human's life after death. It is designed to provide adults with the opportunity to talk about death as being part of the life cycle, which can be a reassuring way of explaining death to children

Are you a sad little bear? A book about learning to say goodbye (Rachel Rivett 2013) Grandmother Bear has gone for ever, and Little Bear is feeling sad. His mother wisely suggests that perhaps asking his woodland companions what saying goodbye means to them will help him understand his loss. Little Bear's day of exploring and asking questions brings him comfort and hope. For the swallows, saying goodbye means flying to warmer lands; for the leaves of the trees it is a chance to be free, leaving the tree at her most beautiful; for the moon it is to return to be with the Sun; and for the Sun it is to rise in another sky and just because Little Bear can't see him doesn't mean he isn't there. This charmingly illustrated picture book will help young children in times of bereavement, loss or change

A first look at: death: I miss you (Pat Thomas 2009) This reassuring picture book explores the difficult issue of death for young children. Children's feelings and questions about this sensitive subject are looked at in a simple but realistic way. This book helps them to understand their loss and come to terms with it.

No Matter what (Debi Gliori 2002) 'I'm a grim and grumpy little Small and nobody loves me at all,' said a small fox. But that's not true and Small's mother is determined to prove that her love is limitless - no matter what! With sparkly foil stars and a small, sturdy board format, this is the perfect story to share with the very young. A beautiful, lyrical, loving book about setting big worries to rest.

Rabbityness (Jo Empson 2012) Rabbit enjoys doing rabbity things, but he also loves un-rabbity things! When Rabbit suddenly disappears, no one knows where he has gone. His friends are desolate. But, as it turns out, Rabbit has left behind some very special gifts for them, to help them discover their own unrabbity talents! This book positively introduces children to dealing with loss of any kind.

For children in bereavement
5-11s

Muddles, puddles and sunshine – interactive workbook (Diana Crossley 2000) Used with a supportive adult this is a useful resource, which when completed will be a wonderful memento that will help the grieving process. --Journal of the National Association of Hospital Play Staff

Badger’s parting gifts (Susan Varley 2013) Badger is so old that he knows he will soon die. He tries to prepare his friends for this event, but when he does die, they are still grief-stricken. Gradually they come to terms with their grief by remembering all the practical things Badger taught them, and so Badger lives on in his friends' memories of him.

Waterbugs and dragonflies – explaining death to children (Doris Stickney 2004) This book uses the analogy of the waterbugs' short life under water as human's time on earth and their emergence as dragonflies into the bright sunlit world above the water as human's life after death. It is designed to provide adults with the opportunity to talk about death as being part of the life cycle, which can be a reassuring way of explaining death to children.

Up in Heaven by Emma Chichester Clark (2004)
Elderly Daisy can't keep up with Arthur any more, and then one day she wakes up to find herself in heaven! How marvellous - now she no longer feels tired or ill, and she can run as fast as she used to! But she worries about Arthur because he is so miserable, and so she sends him dreams to show him where she is, and how happy she is now. One of the questions children regularly ask is: 'Do dogs go to heaven?' This unusual book provides the dog's answer.

When something terrible happens (Marge Heegaard 1991) – A workbook to help children work out feelings about a traumatic event. Traumatic events in the lives of their families, friends or community leave children feeling confused, insecure and frightened. Recreating the event on paper reduces the child's terror and creates feelings of empowerment. Drawing puts the child in charge, providing the opportunity for exploring feelings. With the help of this book, nightmares and post-traumatic stress symptoms can be relieved.

Always and forever (Alan Durrant 2004) 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.

Are you a sad little bear? A book about learning to say goodbye (Rachel Rivett 2013) Grandmother Bear has gone for ever, and Little Bear is feeling sad. His mother wisely suggests that perhaps asking his woodland companions what saying goodbye means to them will help him understand his loss. Little Bear's day of exploring and asking questions brings him comfort and hope. For the swallows, saying goodbye means flying to warmer lands; for the leaves of the trees it is a chance to be free, leaving the tree at her most beautiful; for the moon it is to return to be with the Sun; and for the Sun it is to rise in another sky and just because Little Bear can't see him doesn't mean he isn't there. This charmingly illustrated picture book will help young children in times of bereavement, loss or change.

A first look at: death: I miss you (Pat Thomas 2009) This reassuring picture book explores the difficult issue of death for young children. Children's feelings and questions about this sensitive subject are looked at in a simple but realistic way. This book helps them to understand their loss and come to terms with it.

The Huge Bag of Worries - Children 1st (Virginia Ironside)

When dinosaurs die - a guide to understanding death (Laurie Krasny Brown, Marc Brown 1998) An excellent resource for children when they try to grasp the concept of death and understand grieving, recommended for children who have faced or are facing loss, but also for any child even before an urgent need presents itself.

“It must hurt a lot” – a child’s book about death (Doris Sandford 2014) All children experience loss. It is a part of growing up. When Joshua's puppy is killed by a car accident he learns that some surprises come wrapped in the "package" of loss. We encourage adults to talk about these gifts with children. Sensitive, caring adults are made not born. The book is written for children ages 5 - 11 years.

Heaven (Nicholas Allen 2014) Dill the dog knows his time is up so he packs his case and tells Lily, his owner, that he's off "up there". "Can I come too?" asks Lily. "Er . . . not yet," replies Dill. While he is waiting for the angels to collect him, Dill explains to Lily what he thinks heaven is like: hundreds of lampposts to pee against, lots of whiffy things to smell and bones everywhere - with meat on them! But Lily completely disagrees, she thinks heaven is quite different. Luckily, they agree to disagree just in time for a fond, and very poignant, last goodbye.

When someone has a very serious illness (Margee Heegarde 1991) A workbook to help children deal with feelings about serious illness. An excellent resource for helping children learn the basic concepts of illness and various age-appropriate ways of coping with someone else's illness.

When someone very special dies – children can learn to cope with grief (interactive workbook) (Marge Heegaard 1991) A workbook to help children work out feelings about death. Heegaard provides a practical format for allowing children to understand the concept of death and develop coping skills for life. Children, with the supervision of an adult, are invited to illustrate and personalise their loss through art. When Someone Very Special Dies encourages the child to identify support systems and personal strengths

What does dead mean? – the 'big questions' (Caroline Jay and Jenni Thomas 2012) What Does Dead Mean? is a beautifully illustrated book that guides children gently through 17 of the 'big' questions they often ask about death and dying. Questions such as 'Is being dead like sleeping?', 'Why do people have to die?' and 'Where do dead people go?' are answered simply, truthfully and clearly to help adults explain to children what happens when someone dies. Prompts encourage children to explore the concepts by talking about, drawing or painting what they think or feel about the questions and answers.

Sad isn't bad – a good grief guidebook for kids dealing with loss (Michaelene Mundy 2004)

For children in bereavement
11-16s

What on earth do you do when someone dies? (Romain 2003) Trevor Romain knows, because it happened to him when his father died. This book can help you through a painful time. Trevor answers questions you might wonder about--"Why do people have to die?" "Is the death my fault?" "What happens to the person's body?" "How can I say good-bye?"-in simple, honest words. He describes the strong, confusing feelings you might have and suggests ways to feel better. He tells you it's okay to cry, talk about the death, grieve ... and go on with your life.

Michael Rosen's Sad Book (Michael Rosen, Quentin Blake 2011) It chronicles Michael's grief at the death of his son Eddie from meningitis at the age of 19. A moving combination of sincerity and simplicity, it acknowledges that sadness is not always avoidable or reasonable and perfects the art of making complicated feelings plain.

Out of the blue: making memories last when someone has died (Winston's Wish) 'Out of the Blue' has been written and designed specifically for teenagers with the aim of supporting them through their bereavements with a range of activities.

A Greyhound of a Girl (Roddy Doyle 2012)
12 year old Mary's beloved grandmother is near the end of her life. Letting go is hard - until Granny's long-dead mammy appears. Her ghost has returned to help her dying daughter say goodbye to the ones she loves. But first she needs to take them all on a road trip to the past. A Greyhound of a Girl is a perfectly-pitched, funny and tender tale about four generations of an Irish family, and the special bonds between mothers and daughters. It will entrance readers from 10 to adult.

Listen to me (Listen to me project) – Secondary school children in Highland on subjects of love, loss, anger, guilt, fear.

You just don't understand (Winston's wish) offer guidance to parents, carers and professionals to support a bereaved child or young person.

The death and life of Charlie St Cloud (Ben Sherwood 2005) As a boy, Charlie St Cloud narrowly survived a car crash that killed Sam, his little brother. Years later, still unable to recover from his loss, Charlie has taken a job tending to the lawns and monuments in the New England cemetery where Sam is buried. When he meets Tess Carroll, a captivating, adventurous woman in training for a solo sailing trip around the globe, they discover a beautiful and uncommon connection that, after a violent storm at sea, eventually forces them to choose between death and life, past and present, holding on and letting go. *The Death and Life of Charlie St Cloud* is a romantic and uplifting novel about second chances and the liberating power of love.

For children with learning difficulties

Understanding death & dying 1. A guide for families and friends
2. A guide for carers and professionals BILD

When somebody dies (Books beyond words) – A book without words for people with learning disability (Sheila Hollins & Noelle Blackman 2003) Everyone feels sad when someone dies. People with learning disabilities have the same feelings of grief as anyone else, but they are seldom offered the help and support that other people are given. Mary and John are both upset when someone they love dies. By attending regular counselling sessions and from the comfort and companionship shown by friends, they learn to feel less sad and to cope with life better and better as time passes. This book shows people with learning disabilities that they need not be alone when dealing with grief.

When Mum died/when Dad died (Winston's wish) Many people can understand pictures better than words. Books Beyond Words tell stories about important or difficult events that happen to people in their lives. The pictures speak for themselves. There are around 30 different titles in the series: Books Beyond Words can be used by anyone with learning or communication difficulties, and those with literacy problems. People with learning disabilities trial the pictures before publication to ensure they can be readily understood.

SeeSaw hand in hand via seesaw.org.uk

Stillbirth/miscarriage

We were going to have a baby, but we had an angel instead (Pat Schwiebert 2003) Created especially for children who are suffering the loss of their families pregnancy.

Goodbye Baby: Cameron's Story (Gillian Griffiths 2010) This book provides comfort, understanding and reassurance for young children who have been affected by miscarriage in the family.

Rory's Star – (Scottish Cot Death Trust)
Rory's Star is aimed at pre-school children and explores how a family copes with cot death. We meet Rory the new member of the family and follow life before Rory's death. We meet Rory's big sister and see how they enjoy going to the park, walking to nursery, just being a happy family. Then, suddenly Rory has gone, everything changes and Rory's big sister has to adjust to life without her brother.

About the other children
Our children's friends
(SANDS) – loss of baby
Toby's tiny tot
Mainly for fathers

Road traffic accident

Is Daddy Coming Back in a Minute?: Explaining Sudden Death to Pre-School Children in Words They Can Understand (Elke Barber 2012)
This book explains (sudden) death to very young children in a way they can understand for their age and stage of development. It is based on a true story, written by a parent after her 34 year old husband died very suddenly and unexpectedly and the conversations she had with her young son.

Someone has died suddenly / someone has died in a road crash (Mary Williams via suddendeath.org) – **5-11s** Someone has died in a road crash is a children's book for all ages, taking children step by step through practical things such as funerals and police investigations and exploring normal emotions and feelings. The book is colourful and is narrated by two children who have been bereaved in a road crash who give caring and helpful tips. The book is meant to be read by a child with a parent or carer.

Vicky angel (Jacqueline Wilson 2001) – **11yrs+** Jade is so used to living in the shadow of Vicky, her loud, confident best friend, that when a tragic accident occurs, she can hardly believe that Vicky's no longer around. But Vicky's a sparky girl who's not going to let a small thing like being dead stop her from living life to the full! Whether Jade is in lessons, out running or tentatively trying to make new friends, Vicky is determined to make her presence felt .

The death and life of Charlie St Cloud (Ben Sherwood 2005) **– 11yrs** As a boy, Charlie St Cloud narrowly survived a car crash that killed Sam, his little brother. Years later, still unable to recover from his loss, Charlie has taken a job tending to the lawns and monuments in the New England cemetery where Sam is buried. When he meets Tess Carroll, a captivating, adventurous woman in training for a solo sailing trip around the globe, they discover a beautiful and uncommon connection that, after a violent storm at sea, eventually forces them to choose between death and life, past and present, holding on and letting go. *The Death and Life of Charlie St Cloud* is a romantic and uplifting novel about second chances and the liberating power of love.

Loss of a parent or grandparent

Is Daddy coming back in a minute?: Explaining sudden death to Pre-school children in words they can understand (Elke Barber 2012) – **under 5s**explains (sudden) death to very young children in a way they can understand for their age and stage of development.

Samantha Jane's missing smile: a story about coping with the loss of a parent (Julie Kaplow 2007) – **5-7s**Since Samantha Jane's dad died, she has been sad and quiet, keeping to herself. One day, her neighbour Mrs. Cooper gently asks her about her missing smile, and Sammy Jane begins to open up about her grief, her worries, and her confusion. Sammy Jane's mother joins her daughter in Mrs. Cooper's garden, and helps her further with accepting and responding to her profound loss.

Milly's bug-nut (Jill Janney – Winston's wish 2012) **– 7-11s**'Milly's Bug-nut' is the story of a family finding their way through bereavement and of Milly who finds an unexpected answer to her heart's desire.

How Kirsty Jenkins Stole the Elephant (Elen Caldecott 2009)
Kirsty Jenkins adores the allotment her grandfather lovingly tends and, just before he dies, he asks Kirsty to look after it for him. But when horrible Mr Thomas from the council insists it must go to the next person on the waiting list, Kirsty is determined to find a way to keep her promise.

Wipe out (Mimi Thebo 2003) **– 10s+** Eleven-year-old Billy's mother has just died. Billy's father isn't coping too well so Billy goes to stay with his dull Auntie Mary. The death of his mother has taken all the colour away from Billy's world. He sees his Auntie Mary as a grey person, whose dull blue house is shrouded in fog. Billy feels foggy and dull, too, and longs for the colour to return to his life. His mother was a well-known surfer – Kitten Brown – and the author has woven into this novel the buzzing vibes of the surfing world. Waves, movement, colour, VW combis, Cornwall, surfing songs – described through Billy's dreams as he sleeps away his grief. For though Billy's mother is dead, her joyful personality pervades the whole story as Billy, Auntie Mary and Billy's dad all attempt to deal with their grief.

The Charlie Barber treatment (Carole Lloyd 1997) – **11s+** When your young you are made to think that boys shouldn't cry, if they do they are girly and not big and tough, often boys who were upset would be picked on for this reason. Obviously this is totally wrong. This book shows this it is alright to cry, and that often you need to cry and let your feelings out instead of letting them build up inside you. The story is about a boy who looses his mother and has difficulty expressing his sadness.

As big as it gets – supporting a child or young person when a parent is terminally ill (Winston's Wish) **– 7s+**

What's heaven? (Maria Shriver 1999) – is the story of Kate, a little girl whose great-grandma has just died. She seeks answers, and her mother helps her learn about Heaven.-

7-11s

The Scar (Charlotte Moundliic 2013)
When the boy in this story wakes up to find that his mother has died, he is overwhelmed with sadness, anger and fear that he will forget her. He shuts all the windows to keep in his mother's familiar smell and scratches open the cut on his knee to help him recall her comforting voice. He doesn't know how to speak to his dad any more, and when Grandma visits and throws open the windows, it's more than the boy can take - until she shows him another way to hold on to the feeling of his mum's love.

Missing Mummy (Rebecca Cobb 2012)
'Missing Mummy says so much in a powerful and visual way - the illustrations speak volumes on their own and the minimal text provides a useful prompt to open up conversations around the many questions children may have when they experience the death of someone important in their life.' --Ann Chalmers, Chief Executive, Child Bereavement Charity

Loss of a teacher

The copper tree: Helping a child cope with death and loss (Hilary Robinson 2012) **– 5-10s** When Olivia's teacher, Miss Evans, dies the children at her school are encouraged to think of everything that reminds them of her. Written with great care, touching sensitivity and humour The Copper Tree is about love and legacy and will help children understand that while sadness is an inevitable part of grief, death is not the end for what we leave behind can be everlasting.

Suicide

Beyond the rough rock – supported children and young people bereaved through suicide (Di Stubbs – Winston's Wish) – **7s+**

No time to say goodbye (Carla Fine 2002) **teens+** Suicide would appear to be the last taboo. Even incest is now discussed freely in popular media, but the suicide of a loved one is still an act most people are unable to talk about--or even admit to their closest family or friends. This is just one of the many painful and paralyzing truths author Carla Fine discovered when her husband, a successful young physician, took his own life in December 1989. And being unable to speak openly and honestly about the cause of her pain made it all the more difficult for her to survive.

A special scar: The experience of people bereaved by suicide (Alison Wertheimer 2001) – **teens +**
looks in detail at the stigma surrounding suicide and offers practical help for survivors, relatives and friends of people who have taken their own life. Fifty bereaved people tell their own stories, showing us that, by not hiding the truth from themselves and others, they have been able to learn to live with the suicide, offering hope to others facing this traumatic loss.

Murder or manslaughter

Hope beyond the headlines – supporting children and young people following a manslaughter or murder (Di Stubbs – Winston’s wish) **7s+**

Palliative Care and Bereavement Websites

SAD

Covers stillbirth, neonatal, cot death, child death, Suicide, How to support children, How to support yourself .The site has been created by the cohort of NHS Board bereavement teams around Scotland including paediatrics, with input from SANDS and Child bereavement UK.

http://www.sad.scot.nhs.uk

Grief Encounter
Their vision is that every bereaved child in the UK, and their family, receives access to quality support to help alleviate the pain caused by the death of someone close.
www.griefencounter.org.uk

Cruse Bereavement Care
What you can do to help a child or young person who is grieving?
How to understand the concept of loss in children and young people of different ages.
How to recognise potential complicated grief.
www.crusebereavementcare.org.uk

Partnership for Children
Here are some links to sites that may be helpful to parents and teachers who are trying to help grieving children. Focus on good mental health.
www.partnershipforchildren.org.uk

Together for Short Lives
This Charity and Helpline provide a wide range of free leaflets supporting professionals, families and siblings through palliative care and bereavement.
www.togetherforshortlives.org.uk
For resource projects available from SEND (schools palliative care and grief) P&B

An action plan for Scotland, including the framework for the delivery of palliative care for children and young people
http://www.scotland.gov.uk/Topics/Health/Quality-Improvement-Performance/Living-Dying-Well

CHAS (Children's Hospices Across Scotland)
Available for the parents, siblings and professionals of referred service users.
www.chas.org.uk

Child bereavement UK
Support to families and professionals in anticipation of death and through bereavement.
www.childbereavementuk.org

Winston's Wish
A website particularly suited for sudden deaths and suicide, with area for school support.
www.winstonswish.org.uk

Hope again
A website particularly developed to meet the bereavement needs of young people.
hopeagainorg.uk

Smart grief
A quick pictorial guide to give to children to help them to understand their feelings.
www.smartgrief

Good life, death, grief
Quite a generalised resource but does have links to suitable websites for parents and children. Includes whole school approach to supporting loss and bereavement.
www.goodlifedeathgrief.org.uk

Seasons for Growth
Training programmes for staff.
www.seasonsforgrowth.org.uk

For children with learning disability
www.seesaw.org.uk
www.beaconhill.n-tyneside.sch.uk (Information- policies- quality)

Macmillan
Mainly for professionals or young adult focused.
www.macmillan.org.uk

CLIC-Sargent
For parents, children, teenagers and their siblings.
http://www.clicsargent.org.uk c

Teenage Cancer Trust
www.teenagecancertrust.org.uk

Neonates, babies or 1-5yrs
SANDS
Supporting parents of very ill babies or where there has been an intrauterine death, stillbirth or neonatal death.
www.uk-sands.org

Scottish Cot Death Trust
Although a misnomer, this charity supports any type of sudden death of any pre-school age child.
www.scottishcotdeathtrust.org.uk

SIMBA
Supports memory making activities for parents and siblings of babies who die at or soon after birth (up to 6 months).
www.simbacharity.org.uk

BLISS
For babies born premature or very sick.

www.bliss.org.uk

Lullaby trust
Support for families who have lost a baby through Sudden unexpected death/cot death.
www.lullabytrust.org.uk

Sudden deaths/suicide/murder
For road deaths.
www.brake.org.uk

For suicide.
http://uk-sobs.org.uk
www.samaritans.org/your-community/supporting-schools
For suicide/murder.
www.petal.com
For all sudden deaths.
www.suddendeath.org.uk
For suicide/mental health problems.
www.youngminds.org.uk

CROCUS
Highland group for bereaved children.
www.crocusgroup.org.uk

Highland Hospice
For families of those children linked to hospice only.
www.highlandhospice.org

Appendix 1

RESPONDING TO TRAGIC EVENTS
GUIDANCE FOR SCHOOLS:
WORKING WITH THE PSYCHOLOGICAL SERVICE

Highland Council Psychological Service
Works for Positive Change

The Highland Council Psychological Service Responding to Tragic Events Guidance for Schools - working with the Psychological Service

The Highland Council
Psychological Service

Responding to Tragic Events Guidance for Schools - working with the Psychological Service

Updated April 2016
Review 2019

Contents

HIGHLAND COUNCIL PSYCHOLOGICAL SERVICE PRACTICE PAPER
RESPONDING TO TRAGIC EVENTS
PART ONE – OPERATIONAL GUIDANCE

Introduction

A tragic event is an incident, usually sudden, which involves the experience of personal distress to a level that has the potential to overwhelm individuals. These incidents are wide-ranging and unpredictable in their form. They include bereavement as a result of the death of a member of the school community - for example, following an accident or illness or traumatic incident in the local community affecting the school.

When such an incidence occurs, the first point of contact for a Headteacher would be the Area Office. The Psychological Service is also often contacted when such crisis occur.

A flexible and sensitive range of responses is required, based on sound psychological understanding of the variety of reactions and needs of both children/young people and adults at such times.

The aim of this practice paper is to provide information and checklists to help a school through such an event or to help with forward planning. It therefore provides guidance on practical steps that may help as well as more general information on bereavement.

It is very useful for schools to use the checklist below when responding to such an event.

The Psychological Service

The Highland Council Psychological Service can offer support to those likely to have important responsibilities to fulfil in the event of a tragic event following the principles below.

Principles

If required communication between the school and the Psychological Service should be established quickly and clearly. This work would usually take priority over other arrangements made by the school's liaison educational psychologist.

The work of the Psychological Service in the event of a tragic event should be guided by the following principles:

- The school's liaison psychologist will normally take primary responsibility for the work, but may be supported by other members of the Service, as well as other members of the school's Care and Learning support team.
- Flexible and responsive support will be available in which individual and institutional needs will be carefully considered.
- As in all other areas of work, the **least intrusive most effective intervention** will be offered.

School Response - Operational Guidance

TASK	Timescale	Responsibility
1. Obtain factual information at start of crisis *Carefully check accuracy of information and source.(See also Task 1 below)*	immediate	
2. Contact Area Office/ Education managers	immediate	
3. SMT gather for an up to date briefing *Put policy into action which may include contacting parents and carers of children directly involved including siblings who attend other schools.*	within hours	
4. Call a staff meeting which could include those involved in working in the school community, to give information *Brief staff on dealing with the media – this should only be through the Headteacher or nominee in consultation with press office (be aware of the personal circumstances of staff). In consideration of the impact of information spread by social media all staff should follow guidelines of behaviour as outlined in Highland Council Policies – Social Media and ICT. Teaching staff should also follow GTC* guidance on the use of ICT and social media (* web links below)	same day	
5. Dealing with enquiries *Those manning the phones are given a prepared, factual statement.*	ongoing	
6. Establish a support team – clearly identify roles within the support team *This can include negotiated roles with school's liaison EP, PMHW, Practice Lead, school nurse, Child Protection advisor and other support services where necessary.*	within hours	
7. Inform pupils in small groups/classes/assembly as appropriate *Adults who have been identified as part of school's support team, Headteacher or nominee deliver the factual information simply and clearly (with consideration given to the personal circumstances of members of staff).* (See also task 7 below.)	same day	
8. Inform families *This could be in the form of a letter to go home at the end of the day. Ensure a translator is available as required and that letters are available in all relevant languages as soon as possible.* (Task 8 below)	same day	
9. Arrange a support meeting for staff involved in crisis *This could be with school EP or member of support team as required.*	same day	
10. Arrange and inform pupils of a safe place for pupils involved – to talk as they need with appropriate staff available	ASAP	
11. Consider a whole school assembly *Consider support for this e.g. Church representative. Be aware of cultural diversity (Appendix B provides information about Religions and Beliefs about Death).*	Next day	
12. Staff continue to be aware and sensitive to the needs of the pupils, listening as needed	next few days	
13. Be aware of high risk pupils and staff e.g. wider family network at a different school, children and/or adults undergoing own personal trauma	next few days and weeks	
14. Identify need for group or individual intervention *Consult with extended support services as appropriate. If agreed in discussion between SMT and EP/CSW/ PMHW about their involvement e.g. meeting staff and/or pupils individually then schedule for meetings agreed jointly.*	Weeks/months	
15. In the case of a child being harmed/ abused school to follow child protection procedures	ongoing	

Website references*
www.highland.gov.uk/downloads/file/4469/social_media policy_and_guidance
www.highland.gov.uk/downloads/file/10924/information_and_communications_technology_-_acceptable_use_policy_ict_aup,
https://highlandesafety.wordpress.com/downloads/
www.gtcs.org.uk/web/FILES/teacher-regulation/professional-guidance-ecomms-social-media.pdf

Operational Guidance - Further Details on Tasks

Task 1 - For task 1 it is very important to obtain factual information at the start of a major incident News of tragic events can occur in a number of ways – a Head teacher may find out directly from a parent, rumours may be circulating for a few hours e.g. verbal, social media, or there may be an official announcement from a credible source. For a while, those people managing the situation may have to tolerate an incomplete picture of events – the school's action and planning should be based upon the established facts.

Task 7 – Further advice for informing pupils in small groups
The following guidelines may help in informing children of a death or serious illness or accident:

1. Identify those children who had a close relationship with the hurt, ill or dead person so they can be told together as a separate group.

2. Provide a brief context, and then give the news in simple terms. For example:
   I've got some really sad news to tell you today that might upset you. There is an illness called cancer. Sometimes people with cancer get better, but other times people die from it. John has been ill with cancer for a long time. I have to tell you John died yesterday.
   Or
   Sometimes people have accidents at work, at home, at school or on the road. People may be hurt or injured in the accident and they may have to go to hospital for treatment. I have some bad news to tell you that might upset you. Yesterday Stephanie was in an accident and she was very badly injured.

3. Answer questions factually, avoiding using euphemisms like "passed away", or "lost". Use the words "dead", "died" and "death" in context. In subsequent discussion refer to the name naturally – for example, *John died from cancer* or *yes, we're all going to miss Satvinder*.

4. Be prepared for children to say or do the unexpected. Experience has shown some responses or apparent lack of response may be upsetting for adults. No apparent response does not mean that a child does not care.

Task 8 – Further information for informing families and wider communities
Inevitably, bad news of tragic events can travel quickly around the school community, often distorted along the way. If possible, the management of the school should quickly provide a brief written statement, establishing the known facts. For example, in one school, after a pupil died from an illness, rumours circulated that the illness may be contagious. The Headteacher knew that it was not, and that afternoon included this information in a more general letter sent to all parents that informed them of the child's death. In another school, a rumour circulated that the school would be closed the next day – the Headteacher sent a letter assuring parents that the school would be open as normal.

How Schools Can Help After a Tragic Event

Schools should seek advice and support from Highland Council Education management on matters such as dealing with the press or engaging relevant agencies (such as Police or Children's Services) to act together with the school.

Classroom Management

Maintain normal classroom routine or re-establish it as soon as possible. If teachers themselves find this difficult ensure buddy support or team teaching is available.

Although pupils may benefit from opportunities to discuss what has happened and express their feelings about this, there is some security in knowing that their school life is continuing as usual under the guidance of responsible adults.

Some adjustment to the curriculum may be helpful. It may not be a good time to introduce new material. 'Busy work' may be particularly helpful to pupils – a temporary avoidance of more reflective tasks and a focus on more active ones. Also, encourage resumption of extra-curricular activities – for example, after school clubs or team sports.

Classroom Support

Consider providing opportunities for children to explore their feelings e.g. talk, play. If possible, the class teacher should take an active role in these sessions. There could be one or more sessions, possibly structured around this four stage process:

1. Providing facts about the incident

This is the most important task of the process. It involves providing the children with the facts as far as they are known and dispelling rumours. Rumours often proliferate following a tragic event, and establishing an accurate picture is a key step for children in coming to terms with what has happened.

2. Sharing stories

Children are encouraged to give their accounts of the event, or how they heard about it. This will encourage the development of a shared understanding, and the facilitator can make links between accounts. For younger children it may be more helpful to encourage non-verbal expression – for example, through art activities.

The teacher should also encourage the sharing of the children's feelings and reactions since the event. Here the role is to explain that their reactions are normal responses to abnormal circumstances, that these will pass, but more help will be available if any pupil feels they cannot cope.

3. Empowerment

We need to help the children regain a sense of control. In some situations it may be appropriate to generate strategies for prevention of a reoccurrence of the event. Pupils can also be helped to identify strategies that will help manage crisis symptoms – for example, the importance of adequate sleep, eating and exercise.

4. Focus on the future

This part of the process attempts to mark an ending of the event and a turning to the future. Where an incident has involved death, planning memorials or writing letters of condolence can help in this process. It should be possible to discuss funeral arrangements, and whether the pupils should attend. Alternatively, for people who have been physically injured, writing 'Get Well' cards would also fit naturally. If a fellow pupil will be returning to school after some major event, the other pupils may want to think about how they will encourage that return and support the pupil through an uncomfortable period.

At this point, re-iterate the message about the normality of the children's reactions to the event and the fact that more help will be available if needed.

HIGHLAND COUNCIL PSYCHOLOGICAL SERVICE PRACTICE PAPER
RESPONDING TO TRAGIC EVENTS
PART TWO – SUPPORTING CHILDREN / YOUNG PEOPLE

What Grieving Is…

There is no formula for grieving. People vary in their response to loss. Similarly, there are no prescribed time scales for grief, although most achieve some degree of resolution and acceptance eventually.

When someone close to us dies we experience grief and go through a process of mourning. The experience is both emotional and physical.

The way children grieve is often described as 'puddle-jumping': moving rapidly from great distress to physical activity, for example. This is normal.

Supporting Children / Young People Through Bereavement Process

Generally pupils may lack concentration, experience tiredness in school or show more immature behaviours (for example, sucking thumb or physical clinging). Teachers will need patience in managing withdrawn behaviour, irritability or increased nervousness and anxiety. This may happen immediately or after some time. It would therefore be important to alert appropriate staff particularly at times of transition.

There is a developmental aspect to children and young people's experiences of grief and sorrow. The pre-school or nursery child will experience a sense of loss but may not understand the permanence of the loss. During the primary school stage, children will develop an understanding of this permanence, and this may go along with feelings of guilt and responsibility for the death. In adolescence, powerful emotions of grief are likely to be experienced which may lead to the young person questioning the meaning of life. (See www.childbereavementuk.org for further information.)

When supporting pupils, show that you are concerned and willing to discuss the bereavement. Make opportunities for the child to have a private discussion – for example, through staying behind to help with a task. However, if the child does not want to talk, respect their right to privacy. The child may not want to express their feeling at all, or may prefer to use painting,
If the child *does* want to talk:

- listen with warmth and full attention
- avoid emphasis on advice or interpretation
- active listening skills will be helpful, such as simple acknowledgement of what has been said, reflecting back what the child has said, naming the emotions you hear, and summarising briefly what has been said
- answer questions as accurately and honestly as you can
- try to give the message that the feelings of bereavement are natural and normal

Some people may not feel they are the 'best person' to do this kind of thing, but if they are trusted by the child, and have a pre-existing relationship, then they may be more useful than a more experienced, but unfamiliar, adult.

However, if the teacher, for whatever reason, would rather not attempt to engage the child, then the management team in the school must be sensitive to this and offer someone else.

Try not to single out the child for special privileges – they need to feel part of their peer group and should be expected to take part in the normal activities of school and classroom. At the same time, allowances may have to be made in terms of the quantity, quality and type of work expected of the child.

The pupil's friends may benefit from a discussion to help them explore the best ways of being supportive.

Ensure that other members of staff are aware of what has happened, so that the pupil is not unnecessarily hurt by a chance remark.

It will be important for a teacher supporting a pupil to be aware of the family's cultural or religious influences, particularly beliefs and attitudes to death. For example, some cultures resist talking about death openly, whereas others have formal procedures relating to loss and bereavement.

Long term, remembering special days (such as a birthday or the anniversary of the death) may be helpful. It may be a particularly difficult day, but teachers can acknowledge the loss, whilst at the same time helping pupils to realise how far they have come. (www.winstonswish.org.uk offers helpful suggestions.)

What are they feeling? (From Winston's Wish Schools' Information pack)

Children aged 2 to 5

Children aged between 2 to 5 years think that death is reversible and that people who have died can come back. Their thoughts are characterised by what we call "magical thinking". Children can be convinced that it was something they said or did or thought that caused the person to die. The flip side of this thinking is that they can believe their words, actions or thoughts can bring the dead person back. They need to be reassured repeatedly that the death was not their fault. Children's thinking in this age range is also concrete – they cannot grasp abstract concepts or roundabout ways of saying things. Instead use specific concrete words such as "Mummy has died" and give specific explanations about why the person died. Don't be afraid to be honest and tell your child if you don't have an answer.

It is not unusual for children of this age to revert to behaviour patterns they had when they were younger such as bed-wetting, use of a security blanket or thumb sucking. Try to be tolerant. In time, these earlier behaviour patterns will probably disappear again, once family life resumes.
One of the most difficult aspects of a child's grief at these ages is how they ask the same questions over and over again in an effort to begin making sense of their loss. Children are

naturally curious and they want to make sense of what is happening in their world. Their repeated questions are not a sign that your explanations aren't good enough - it is just the way they do things at this age. Reading books on death and loss, playing, drawing and giving them opportunities to identify and talk about worries and feelings will all help them deal with the loss. When they experience a death in this age range they are at their most helpless and are most dependent on adults to regain their balance.

Children aged 6 to 9

In this age range the child begins to develop an understanding of death as irreversible and something that will happen to all living things but they may be confused about it. It is not uncommon for children to think of death as something spooky, like a zombie or a spirit that comes to get you. It is important that their specific worries are spoken about, that they share bad dreams and are told that what they're feeling is normal. Children are reassured by having their worrying and negative thoughts talked through, giving them skills and confidence to be in charge of them.

Children may display what you feel is an unhealthy curiosity with issues such as what a dead body looks like and what happens to a body after a person has been dead for some time. This curiosity is natural and they will benefit from clear explanations. They may worry about how the person who has died will eat, breath and keep warm. It is important to give them information and tell them that once someone has died, the body doesn't feel any more and they don't get hungry.

Children at this stage may complain of a sore tummy, headaches or just generally not feeling well. These are what we call 'somatic' complaints, where unexpressed feelings and emotions can lead to physical symptoms or discomfort. Somatic complaints are normal but it is important that routines are maintained while gently acknowledging when someone important dies.

Children this age may have difficulty expressing feelings verbally and may retreat into themselves. In dealing with their feelings of helplessness, you may notice increased aggression. It is important to avoid clichés such as "You're such a brave boy/girl". Children will interpret this that you want or need them not to share their feelings. They need you and other important people in their lives to show them that it's OK to express their feelings.

Children aged 9 to 13

In this age range children are much more aware of the finality of death and the impact the death has on them. They are able to understand death as both concrete and abstract.
Children may experience difficulties in their interactions with their peers. The death of someone important can make them feel different at the very time they want to be the same as everyone else.

It is important to find ways to build their self-esteem. Children at this age are beginning to think of the longer term consequences of the loss of the relationship. They are aware of the loss they feel in the present but also of the losses they will experience in the coming months and years when they encounter certain important milestones or occasions and realise that they won't be able to share these with the person who has died.

At this age children are beginning to move away from dependence on the family and they start to form important relationships with other children. The death of someone important can easily destabilise them, leaving them feeling unsafe and more dependent on the family. Their ability to manage their feelings may be disrupted and lead to mood swings or more definite ups and downs in their feelings. Big emotional releases (such as anger or distress) are not uncommon but can be scary for children at this stage. They will benefit from your willingness to listen and your assurances that the feelings are normal.

Adolescents

Friends and peers are increasingly important as young people develop their ideas of who they are and what is important to them. They want to be accepted by other important people in their lives. Their bodies are changing; they are aware of all sorts of possibilities for themselves and are more aware of the future - their future. It is quite common for risk-taking behavior to increase during adolescence as young people test the boundaries.

They may struggle to make longer term plans as the death of someone important causes them to reflect on “the meaning of life” and ponder on the question “what’s the point?” Or you may find that they are so busy with different activities they don’t stop to reflect. This can be an effective way of keeping intense feelings under wraps if they are worried about losing control of their emotions.

If you notice a teenager who is withdrawing, acting very matter of fact and detached, or angry and protesting, then remain available for them - but don’t push. Your job is to remind them that you’re there and if they’d prefer to speak to someone else you’ll help them find peers or other trusted adults to support them. Although an adolescent’s growing process is most like an adult’s they are still going through important emotional development at this age and are not ready to manage adult responsibilities even if at times they think they are adult. They need to be reassured of your love and support and to know that the limits you set are still enforced.

Grieving Children and Young People

When a child or young person experiences the death of someone important to them, they need not only need to adapt to living with their grief within the family home, but also to the challenges of a changed life in the outside world. This will include school. Children spend a large proportion of their time at nursery or school and their social life is often centred on friends made there. Grieving children and young people highlight how school responds is very important to them

What school can offer a grieving child just by carrying on with normal daily routine
In order to protect immediate family from further upset children/young people sometimes find it easier to talk to someone not directly involved such as a familiar trusted teacher. Going to school can give a sense of normality and many choose to return immediately after a death has occurred for this reason. Others need to take a few days off, but the longer they are away the harder it is to return. When grieving, children of any age often view school as a place where they can have some time away from overwhelming emotions and sadness.

With parent permission it helps that staff know that a child is grieving, who they are grieving for and when the death occurred. Some children are reluctant for this information to be given out but if everyone has the basic facts this prevents insensitive remarks being made by teachers and others because they are unaware of what has happened. Certain lesson topics may bring back painful reminders of the circumstances surrounding the day. This unintended upset can cause real distress for a child and the member of staff concerned.

How a school can help
Below are examples of what school can do to help a grieving child:

- To meet and talk to the child about how they would like their return to school managed and how best to break the news to the friends and classmates.
- To acknowledge what has happened but without making a fuss so that the child does not feel the spotlight is on them.
- Someone of the child's choice that they can talk to should they feel the need to do this.
- A member of staff who will keep a lookout for the child at school who will be the person to contact if a parent/carer has any queries or concerns.
- A 'time- out' system to enable the child to have some space away from the hustle and bustle if they feel overwhelmed by powerful emotions. Some schools can organise this as time away from class but still with an adult others have a quiet corner in the classroom.
- A record of key dates such as the anniversary of the death which can often act as a trigger for children to revisit their grief.
- Some flexibility around deadlines for handing in work grieving is exhausting as a child or young person may struggle to concentrate on school work.

(Adapted from leaflet by Child Bereavement UK - Grieving Children and Young People: the role of school)

Information on Bereavement by Suicide

The death of someone important can cause great pain and sadness whatever the cause of death; however families bereaved through suicide also have to face additional pressures and pain. Suicide leads to the involvement of many strangers e.g. police officers, press, procurator fiscal and a family's private grief can become very public.

The extent of the shock of suicide is often underestimated. The loss of what might have been is even more powerful when a death is by suicide because of the decision to die.

Bereavement by suicide shares characteristics with other bereavements and it is also different. Understanding how and why it differs is helpful when you are supporting children / young people who have been bereaved in this way.

The grieving process is often complicated and typically lasts longer than other types of bereavement – significantly effects may still be felt for many years after the death. Although there is no single or correct way to experience any bereavement there are many common reactions and factors in bereavements by suicide including:

- Circumstances of the loss
- Emotional and physical reactions
- Post-traumatic stress
- The survivors questions – "why?" and "what could I have done?"
- Stigma and isolation
- Family and community tensions
- Other prejudices
- Lack of privacy
- Investigations
- Practical concerns

Circumstances of the loss

A death by suicide is usually sudden, often unexpected and may be violent. These factors increase the degree of shock and trauma experienced compared to many other types of bereavement. Survivors may struggle to make sense of what has happened and fundamental beliefs may be challenged.

Emotional and physical reactions

Bereavement by suicide can bring an intensity and range of emotions and physical reactions which may be unfamiliar, frightening and uncontrollable.

Emotional reactions are often complex and people may find that they are experiencing a bewildering range of feelings including guilt, anger, shame, rejection, sadness and fear. People who have been bereaved by suicide may become vulnerable to thoughts of suicide themselves.

Physical reactions may include tightness in various body parts, stomach pains, sleeplessness and poor concentration.

Post-traumatic stress
Those who have been bereaved by suicide may have symptoms of post-traumatic stress. If the person witnessed the death or found the body, they may suffer from flashbacks or nightmares. This can also happen even if the person did not see the body, but cannot stop imagining what happened – and imagination may be worse than the reality.

Survivor's questions
Most people bereaved by suicide are haunted by two questions - "why did the person take their life?" and "could I have somehow prevented it?". These are impossible questions to answer and eventually the person may have to either have to accept that they will never know or settle on an answer which they can live with.

It is natural that the bereaved person will take some considerable time in exploring these questions and it is an important part of the grieving process. However it can also be damaging if they are unable to reach a stage where the questions occupy less of their thoughts or if they cannot find an answer they can accept. Self-esteem, confidence and hope can be severely compromised.

Stigma and isolation
Death by suicide, even more than other types of bereavement, makes many people uncomfortable and unsure how to react. There is still a stigma attached to suicide, rooted in centuries of history and this generates misplaced associations of weakness, blame, shame or even sin or crime. This stigma can prevent people from seeking help when they need it and others from offering support when they want to.

There may be a desire to deny that the death was a suicide – this may be driven by cultural values or from a sense of denial or of shame. This can create further confusion in an already complex situation.

Many people who have been bereaved by suicide find that they feel isolated. Others may avoid them, perhaps not knowing what to say or because they don't want to upset the person. The sense of isolation may be especially acute if the bereaved person perceives other people to be uncaring or judgemental. Some people are unlucky enough to receive particularly thoughtless and malicious comments.

It may also be that the bereaved person avoids contact themselves – they may struggle to share their own feelings because they are fearful themselves of what they are experiencing, they don't want to upset other people or they may worry about how to answer questions such as "how did he die?"

Family and community tensions
Whilst family and friends are often a great source of support, they can also be a source of tension and conflict. Sometimes families struggle to communicate, protective instincts kick in and they may be worried about causing more pain or about having a different view or feeling to others. Because the range of feelings and emotions experienced after a suicide can be so unfamiliar and frightening, people may be uncomfortable or scared to share.

Existing tensions and difficulties in family relationships can be surfaced as a result of the shock of trauma. Some people cope with their pain by blaming another person for the death – this may go as far as excluding them from the rest of the family, denying them the opportunity to attend the funeral and withholding information about the investigation. This can lead to huge rifts and a deep sense of hurt and isolation being added to the loss.

Lack of privacy

When someone dies by suicide, it can be difficult to maintain privacy. There may be emergency services at the scene and visits from police. There may be media attention – this can happen when the person dies and may be repeated after the investigation by the coroner or procurator fiscal. The inquest is held in a public court of law and anyone can attend – in certain circumstances reports will be made which remain on publicly accessible databases.

Investigations

The investigation by the coroner or procurator fiscal is a source of considerable concern for those bereaved by suicide. The process can be lengthy, the proceedings are unfamiliar and the language is legal and technical. The process is open to public attention and there is often media reporting. There may also be additional investigations e.g. if the death happened whilst the individual was under the care of another agency e.g. in prison or if they were receiving mental health treatment.

In addition to being an added strain, investigations may reveal information about the bereaved person which was unknown to their family and friends.

Practical Concerns

In addition to this, there are other practical concerns such as finances, funerals, returning home and returning to work which the bereaved will need to face.

(Adapted from SOBS, Survivors of Bereavement by Suicide **-** How suicide bereavement is different**)** **http://uk-sobs.org.uk/for-professionals/how-suicide-bereavement-is-different/**

Supporting a Pupil Bereaved by Suicide

Death of a Parent

For children of any age, the death of a parent by suicide brings particular challenges. They are likely to feel abandoned and it can be very hard for children to avoid feeling that somehow they weren't enough of a reason for their parent to keep living.

Talking to children about how the person died will depend on the child's age or level of understanding. If there are young children who have lost a parent or sibling to suicide, a natural response is to want to protect them from knowing what has happened, and to think up an alternative explanation for the death. However, because of the likelihood of overheard conversations, media coverage, gossip and visits from the police, it is hard to keep the cause of death a secret. It is better for children to hear the truth from people who love them than from someone in the playground or on social media: this is a time when they need to feel there are people they can trust. Talking about what has happened is a chance to answer any questions (within the limits of their age and level of understanding) and to check that they have understood what has been said. It is also a chance to reassure them they were not to blame. Ideally, a parent would be the best person to tell the child what has happened – if this is not possible, ask someone they trust to explain what has happened.

If the child has already been given a different explanation for the death, it is possible to go back and change it. For example by saying something like: 'You know I told you that your dad had an accident and that is why he died. Well, I've been thinking about this and I would like to tell you a little more about how he died. I didn't know what to say when it happened, it was such a shock. Now I'd like you to know what actually happened that day.'

Children and young people will have the same range and intensity of feelings as adults but may need help identifying and expressing their emotions. It may be the first time that someone they know has died and even the concept of death is new to them. Understanding suicide can be overwhelmingly difficult and confusing. They may find it very hard to cry: it doesn't mean they aren't as distressed as someone who can't stop crying. The way children grieve is often described as 'puddle-jumping': moving rapidly from great distress to physical activity, for example. This is normal. Some emotions can be strongly felt by children and young people depending on their age and level of understanding. It is common for a child who has been bereaved by suicide to feel that they were in some way to blame – for something they did or did not do; or something they said or did not say. Giving regular reassurance is important.

Young people may become extremely angry – with the person who died, with other members of the family, with themselves. Grief can put a great strain on relationships and young people may fall out with members of the family or with friends. It is also very natural for a child to be scared that someone else in the family may also die by suicide.

They benefit from reassurance. A parent could say something like: ‘I know I have been very upset, angry and shaky since your Dad died but I am not going anywhere. I will get upset, because I am still so sad that he died, but it does not mean I will die the way he did.’ It is natural to be afraid that affected children will grow up believing that suicide is an option. Making it clear that talking about what has happened is allowed, and that it is helpful to share how you are feeling is important. It also helps to explore with them alternative ways of coping with difficulties.

Children may also appreciate being helped with how to answer questions from others: their friends may be very direct and inquisitive. Help them find something they are comfortable saying, for example: ‘My sister died at the weekend. It is very sad. It was suicide. Please don’t ask me for any more information. If I feel I can talk about it, sometime, I’ll let you know.’ Some young people may find it easier to talk and may want to say something like: ‘Please don’t avoid talking about your father just because of what happened to mine. It’s tough but I’d rather we talked about it.’ It may be that other young people, in person or through social media, ask intrusive questions; it can help to have a sentence ready such as: ‘Thanks for being interested, but I’m not going to talk about it so please don’t ask me.’

Death of a Sibling

If a brother or sister dies, the sibling(s) immediately lose someone whom they have grown up with, laughed with, argued with, and with whom they have shared a lot of memories. A variety of feelings might be felt by the remaining sibling(s). The surviving sibling(s) might feel;

- that they should have protected their brother/sister;
- hurt that their brother/sister did not turn to them for support, especially if the surviving sibling is the eldest;
- if there was a troubled relationship, the siblings may feel as though they are left with unresolved issues.

Not only do the remaining siblings not only have their grief and confusion, but they can feel responsible for helping to support their parents with their grief too. It might feel as if they have lost all their family at once if parents withdraw from them into their grief, and it can be hard not to blame the person who has died.

It can be helpful for the surviving siblings to talk through feelings with wider family and friends to get their support.

Death of a Friend

If the person who died was a friend, young people may need intense support; they may have shared things together and they will wonder if there was more they could have done. Their friend may be someone they knew online and other people may not understand the intensity and importance of that connection. It can help if young people know there are places (such as support organisations, school counsellors, helplines) where they can talk about their feelings, as sometimes they may struggle to share their thoughts with other members of the family.

As a friend of the person who died, a child/young person may sometimes feel that their grief and needs can be overlooked and that it is difficult to get their voice heard or obtain support. It can be hard to find themselves in a secondary role after the death, and having little or no involvement in planning the funeral or other arrangements.

A friend may also have particularly intense feelings to deal with if they were the person who knew how low their friend was feeling also the friend who has died maybe knew things about them that no-one else did – and now, no-one does.

Friends can sometimes feel that they are not 'entitled' to any support after someone dies. It is important to remember that what matters is how this loss affects individuals, not whether they were related to the person who died.

(Adapted from Help is at Hand booklet – copies from http://www.supportaftersuicide.org.uk)

HIGHLAND COUNCIL PSYCHOLOGICAL SERVICE PRACTICE PAPER
RESPONDING TO TRAGIC EVENTS
PART THREE – TAKING CARE OF YOURSELF

Coping After Trauma – What Can Help?

The recovery process following a severe trauma will necessarily take some time.
The purpose of this handout is to provide some tips for coping after a traumatic event.

Taking Care of Yourself

Everyone who is in any way involved with a traumatic event may experience trauma reactions. You might experience these reactions if you:

- Were a witness or were involved in the event.
- Arrived upon the scene of the event.
- Had a "near miss" or were almost involved in the event.
- Knew or know others who were killed, harmed, or involved in some way.
- Have a relationship with family or friends of victims.
- Have heard a lot about the event through media or friends.
- Are reminded of other traumatic incidents in your life by this event.

It is important to remember that trauma reactions are normal reactions. It is difficult to predict what type of trauma reactions you will experience following a traumatic event. It is important to allow yourself permission to have your reactions, and take care of them both by yourself and by asking for help from others, as best you can. Many people find it helpful to have information about what constitutes a typical reaction to trauma.

Typical Reactions

Not everyone experiences the same set of responses to trauma, but people typically experience reactions that fall into four basic categories. Here are some reactions that you may be experiencing.

Psychological and Emotional

- Heightened anxiety or fear.
- Irritability and restlessness.
- Feelings of sadness, moodiness, more crying than usual.
- Feelings of helplessness or hopelessness.
- Feelings of numbness or detachment.
- "Survivor guilt" or feelings of self-blame that you escaped the tragedy.
- Re-experiencing of the traumatic event, possible including: intrusive thoughts or images of the event.
- Distressing dreams or nightmares.
- Flashbacks about the event.
- Distress when exposed to events that remind you of the trauma.
- Feelings of estrangement or isolation from others.
- Hyper vigilance (feelings especially attuned to events around you, scanning environment for possible danger).

Cognitive

- Difficulty concentrating.
- Feeling confused or distracted; slower processing thoughts than normal.

Physical

- Headaches.
- Nausea or upset stomach.
- Exaggerated startle response (tendency to startle easily at loud noises).
- Fatigue or feeling slowed down.

Behavioural

- Hyperactivity, or less activity.
- Heightened tendency to behave irritably.
- Withdrawal, social isolation.
- Avoidance of activities or places that remind you of traumatic event.
- Insomnia or sleeping excessively.
- Strong need to talk about the event or read accounts about the event.

You may recognise yourself as experiencing some of the above reactions. Remember that your response is normal. Immediately following a traumatic event you may feel disrupted, dazed, and somewhat confused. You may notice that you are not behaving as you typically would. It is important to take care of yourself as best you can. Here are some self-care suggestions for you.

Coping Tips and Strategies

- Keep in mind that the grieving/coping process will occur differently for each of us. Be as supportive of yourself in your recovery as possible. Remind yourself that it's normal and fine to take the time you need to work through a severe trauma.

- Be aware that you may have different coping needs at different times. Sometimes you may feel like talking, sometimes you may feel like crying, sometimes you may wish to focus your attention away from the crisis completely.

- Allow yourself to turn off the news and get some distance from the crisis when you need to. It's OK (and important) to have time for laughter and fun, even during a time of grieving.

- Get plenty of rest when you're tired. And use the energy you have if you experience hyperactivity at times. Don't force yourself to be active if you don't have the energy, or rest when you don't feel tired.

- Talk to people as much as you need to. Reach out. You may experience a need to talk repetitively about the trauma. If you can find someone who is willing to listen, use her/him to talk to about how you are feeling.

- Spend time with others, even if you don't feel like talking. It can be very comfortable to know you're not alone. Try to find someone or someplace that feels safe and comforting to you, and spend time there.

- Don't make any major life decisions or big life changes if at all possible. This is not a time to put pressure on yourself to do anything out of the ordinary. Concentrate on taking care of yourself.

- Do things that feel good to yourself – take baths, read, exercise, watch television, spend time with friends and family, fix yourself a special treat, or whatever else feels self-caring.

- Allow yourself to cry, rage, and express your feelings when you need to. Try not to numb your feelings with alcohol or drugs; this will only complicate your situation.

- Reaching out to others in a supportive way can sometimes be helpful. Such support may include volunteering time in the community. However, do not feel guilty if you do not have the energy to help others when you are coping with a traumatic event.

The Process of Recovery

It is important to know that recovering from a trauma is a process that may take a long time. The initial response of disruption (perhaps alternating with numbness) may last days, weeks or longer. Don't be surprised if you continue to experience these reactions for longer than you expected. See Appendix 'A Guide for Parents and Carers of Children / Young People Affected By Crisis'**.**

It is impossible to predict how long you will experience effects of the trauma, but usually trauma reactions gradually decrease over time. If you experience another stressful event while recovering from trauma, you may find that your trauma reactions reappear for a while. This reactivation, or delayed trauma response, is perfectly normal.

At any time during this process, you may find it useful to ask for professional help from a counsellor or mental health professional. There are some circumstances under which you should definitely get professional help:

- If you find yourself feeling suicidal or contemplating suicide.
- If you find that your daily functioning continues to be impaired so that you cannot carry out your life tasks.
- If post-trauma fears interfere with your ability to return to certain places or situations that remind you of the trauma.

Further information can be obtained from:

The Highland Council Psychological Service
11/13 Culcabock Avenue, Inverness, IV2 3RG
Tel: 01463 233494

http://www.highland.gov.uk/info/886/schools_-_additional_support_needs/36/psychological_service

PART FOUR - USEFUL RESOURCES

Extended Support Services

The Psychological Service, Primary Mental Health Worker, Practice Lead, School Nurse and Children's Services Workers can offer support to those likely to have important responsibilities to fulfil in the event of a tragic event following the principles below.

The Psychological Service

The Highland Council Psychological Service can offer support to those likely to have important responsibilities to fulfil in the event of a tragic event.

Schools can develop their own Tragic Events Procedure (Being Wise before the Event) with the support of their liaison EP using the guide available in Appendix B.

Involvement as a Result of a Tragic Event

After consultation between psychologist and Head Teacher agreed involvement may include:

- psychological advice, for example, on bereavement and grieving processes in children, on post-traumatic stress reactions or on accessing other agencies
- making resources available to schools which may be useful in supporting children, parents or staff
- being available for children, parents and staff, individually or in groups
- longer term follow up such as considering check-ins at significant dates following the tragic event

Psychological First Aid

Highland Council Psychological Services provides support following a model of Psychological First Aid. For information about Psychological First Aid (PFA) please see Appendix A.

Psychological First Aid recognises that those supporting communities should themselves access support from peers, if they wish, when providing support if there is a tragic event. When a member of the Highland Council Psychological Service is involved in supporting a school community following a tragic event it is important that opportunities for support are available from within the service.

Psychological Service Contact Details

Highland Council Psychological Service
11-13 Culcabock Avenue
Inverness
IV2 3RG Telephone 01463 233494

http://www.highland.gov.uk/info/886/schools_-_additional_support_needs/36/psychological_service

Seeking Further Support

Religious Representations
It may be helpful to involve religious representatives, ministers, priests etc. in discussions about memorial services, special assemblies etc.

The Crocus Group
The Crocus Group offer a service to young people who have suffered from bereavement. They aim to help, support and manage bereaved children/young people. They generally take referrals in relation to children 6 months after they have been bereaved.

The Crocus Group
Child Bereavement Support Service
Raigmore Hospital
Inverness
IV2 3UJ

01463 704000 ext.6092

The Maggie Organisation
www.maggiescentres.org/

National Organisations
www.winstonswish.org.uk
www.childbereavementuk.org
www.crusescotland.org.uk
www.samaritans.org

Samaritans has a service called Step By Step, which can provide support to schools after a suicide through telephone contact in the Inverness area. Several child bereavement services (both national and local) can guide parents on supporting children bereaved by suicide. Some of these have particular programmes of support, such as groups, for children and young people who have been bereaved by suicide.

Training
Seasons for Growth
The Seasons for Growth programme draws upon extensive research in developing a sound educative response to change, loss and grief. Seasons for Growth is an educational programme involving peer support, it does not provide counselling or therapy. It is built upon a recognised model of grief – Worden's Tasks of Grieving.

If you require further information please contact Isabel Shaver at the Highland Council Psychological Service, Culcabock Avenue; Inverness IV2 3RG - telephone 01463 233494.

ASIST

Shown by major studies to significantly reduce suicidality; the ASIST model teaches effective intervention skills while helping to build suicide prevention networks in the community.
Applied Suicide Intervention Skills Training (ASIST) is for everyone 16 or older—regardless of prior experience.

If you require further information please contact Emma Campbell (Primary Mental Health Worker).

Books

Information Books and Leaflets for Adults

Responding to Pupil Bereavement by Lesley Ratcliffe
(Positive Behaviour Management, 2001).
A booklet for teachers, raising awareness of the issues surrounding bereavement.

Giving Sorrow Words by Steven Killick and Stuart Lindeman.
(Lucky Duck Publishing Ltd, 1999).
A video and manual training package aiming to help children and schools deal with loss and bereavement.

Caring for Bereaved Children
(Leaflet from Cruise Bereavement Care, 126 Sheen Rd, Richmond.
ISBN 0 900321 06 7)

Picking up the Pieces Handbook – A Guide for Supporting Children in Grief by Good Grief
(Good Grief Ltd – 2008)
Booklet raising awareness of the issues surrounding bereavement. Gives suggestions of strategies to support the child within your role responding to them in a way that rebuilds resilience.

Wise Before the Event – Coping with Crises in Schools by William Yule and Anne Gold.
(Calouste Gulbenkian Foundation,1993)
Aimed at school staff and governors: a guide for planning responses to any traumatic event.

Multi-Cultural and Religious Practices when Dealing with Bereavement, Loss and Trauma.
(Booklet from Northamptonshire Education Home School Liaison Officers)
A short outline of different approaches to bereavement.

Helping Children Cope with Grief by Rosemary Wells
(Sheldon Press (1988)
A book for adults helping bereaved children.

Workbooks for Children and Young People

Finding a Way Through When Someone has Died by Pat Mood and Lesley Whittaker (Jessica Kingsley)

A workbook by young people, for young people

Talking with Children and Young People about Death and Dying
(Jessica Kingsley)
A workbook designed to help children recognize and express feelings of grief and encourage open communication.

When Something Very Terrible Happens by Marge Heegaard
(Woodland Press, 1991)
A workbook to help children work out feelings about a traumatic event. Traumatic events in the lives of their families, friends or community leave children feeling confused, insecure and frightened. Recreating the event on paper reduces the child's terror and creates feelings of empowerment. Drawing puts the child in charge, providing the opportunity for exploring feelings. With the help of this book, nightmares and post-traumatic stress symptoms can be relieved.

When Someone Very Special Dies. Children Can Learn to Cope with Grief (Drawing Out Feelings Series) by Marge Heegaard
(Woodland Press, 1991)
A workbook to help children work out feelings about death. Provides a practical format for allowing children to understand the concept of death and develop coping skills for life. Children, with the supervision of an adult, are invited to illustrate and personalise their loss through art. When Someone Very Special Dies encourages the child to identify support systems and personal strengths.

Story Books for Young Children (up to about 7 years)
Badger's Parting Gifts by Susan Varley
(Collins, 1985)
A picture book – badger dies but leaves good memories

Fred by Posy Simmonds
(Puffin, 1989)
Fred the cat dies – a positive focus on how Fred will be remembered

Grandpa by John Burningham
(Puffin, 1989)
An account of the relationship between a little girl and grandpa through his ageing, illness and death.

Websites for Adults (many useful resources)
www.winstonswish.org.uk
www.childbereavementuk.org

Website for Children / Young People

www.smartgriefguide.co.uk

http://hopeagain.org.uk - the youth website of Cruse Bereavement Care

APPENDIX A – Psychological First Aid

What is Psychological First Aid (PFA)
PFA is a humane, supportive and practical response to a fellow human being who is suffering and who may need support (Sphere (2011) and IASC (2007). It gives a framework for supporting people in ways that respect their dignity, culture and abilities. Despite its name, psychological first aid covers both social and psychological support.

PFA has been recommended by many international and national expert groups and is offered as an alternative to psychological debriefing (CISD - critical incidence stress debriefing). PFA has a long history but has become more popular since the emergence of research showings dangers of CISD. NICE guidelines recommend that CDIS should not be part of routine practice.

PFA is an approach for assisting people in the immediate aftermath of a crisis to reduce initial distress and to foster short and long-term adaptive functioning. Other characteristics include non-intrusive pragmatic care and assessing needs. PFA does not necessarily involve discussion of the traumatic event; is not compulsory and can be done in multiple sessions. It links those who need more help to services. It deals with practical issues which are often more pressing and create stress. It also improves self-efficacy by letting people cope their own way. PFA has attempted to be culturally sensitive.

PFA seeks to promote:
- safety
- calm
- connectedness
- self-efficacy and group efficacy (belief that one's actions are likely to lead to positive outcomes and feeling able to help oneself)
- hope.

Why Psychological First Aid?
People react to a crisis with a wide range of reactions and feelings. Many people may feel overwhelmed, confused or very uncertain about what is happening. They can feel very fearful or anxious, or numb and detached. Some people may have mild reactions, whereas others may have more severe reactions. How someone reacts depends on many factors, including:
- the nature and severity of the event(s) they experience;
- their experience with previous distressing events;
- the support they have in their life from others;
- their physical health;
- their personal and family history of mental health problems;
- their cultural background and traditions;
- their age (for example, children of different age groups react differently).

Every person has strengths and abilities to help them cope with life challenges. However, some people are particularly vulnerable in a crisis situation and may need extra help. PFA involves the following themes:

- providing practical care and support, which does not intrude;
- assessing needs and concerns;
- helping people to address basic needs (for example, food and water, information);
- listening to people, but not pressuring them to talk;
- comforting people and helping them to feel calm;
- helping people connect to information, services and social supports;
- protecting people from further harm.

What Psychological First Aid is not.

- It is not something that only professionals can do.
- It is not professional counselling.
- It is not "psychological debriefing" in that PFA does not necessarily involve a detailed discussion of the event that caused the distress.
- It is not asking someone to analyse what happened to them or to put time and events in order.
- Although PFA involves being available to listen to people's stories, it is not about pressuring people to tell you their feelings and reactions to an event.

PFA is an alternative to "psychological debriefing". PFA involves factors that seem to be most helpful to people's long-term recovery. These include:

- feeling safe, connected to others, calm and hopeful;
- having access to social, physical and emotional support; and
- feeling able to help themselves, as individuals and communities.

Who is Psychological First Aid for?

PFA is for distressed people who have been recently exposed to a serious crisis event, providing help to both children and adults. However, not everyone who experiences a crisis event will need or want PFA, it is not forced on people who do not want it, but is made easily available to those who may want support.

There may be situations when someone needs much more advanced support than PFA alone. Knowing limits and getting help from others, such as medical personnel (if available), is an important aspect of PSA.

When is Psychological First Aid provided?

Although people may need access to help and support for a long time after an event, PFA is aimed at helping people who have been very recently affected by a crisis event. PFA can be provided on first contact with very distressed people. This is usually during or immediately after an event. However, it may sometimes be days or weeks after, depending on how long the event lasted and how severe it was.

Where is Psychological First Aid provided?
PFA can be offered wherever it is safe enough for to do so. This is often in community settings, such as at the scene of an accident. Ideally, try to provide PFA where there is some privacy to talk with people when appropriate. For people who have been exposed to certain types of crisis events, such as sexual violence, privacy is essential for confidentiality and to respect the person’s dignity.

APPENDIX B - Developing a School's Tragic Event Procedure – Overview

Task – being wise before the event	**Timescale**	**Responsibility** ***<u>Who</u>***
Prior preparation – Do we have the following Information and is it easily accessible (in and out of school) 1. Council Contact numbers for emergency: **Area Office** **Area Office out of office hours number** **Emergency Planning Officer (01463 713479)** **Area Principal EP** ***Any others?*** 2. Do we have up to date class lists/ staff lists/ as well as contact details of all those in the school community? a. **Where are these held?** b. **How could these be located if school premises could not be accessed in the event of a tragic event?** c. **How will we inform families of those involved? Parents/carers of other pupils in school?** 3. Do we need an emergency school direct line (as main line may be dealing with incoming calls). If using a 0800 number what message would be left? *(e.g. I can confirm that there has been a tragic event and those involved will be contacted directly)* 4. How are we going to deal with enquiries? (including media) a. **E.g. HT will alert Area Office in the first instance, who may alert the Press Office.** b. **Who will answer the phones?** c. **Who will prepare the 'script'?** d. **Is there a proforma to log all incoming calls?** 5. Who will be in our support team? a. **Consider people's personal circumstances – for example, it would not be advisable to include someone recently bereaved.**	immediate	

b. Other professionals either you or Area Office would wish to contact e.g. liaison EP. 6. Other local issues you need to consider? 7. How would a tragic event be dealt with in term time? *For example how would things be kept as normal as possible? What type of work may pupils be given if they are in a highly emotional state?* 8. What would happen if a tragic event occurred outside term time? *Who would need to be informed?* *Which part of the school would be open?* *Who would be available?*		

APPENDIX C - Religions and Beliefs about Death

The ways in which people deal with death and the funeral rites they carry out are usually very closely linked with their beliefs about life after death. Below are a brief description of the beliefs and customs from some of the main world religions and information on non-religious funerals.

BUDDHISM

Types of Buddhism:

- Theravada - has remained closest to the original Buddha's teaching
- Mahayana - collection of Buddhists traditions which includes: Zen, Pure Land, and
- Tibetan Buddhism

Buddhists believe:

- in reincarnation
- everything is impermanent and that through meditation become ‘awake’ to this reality
- there is no permanent 'soul', people are made up of interrelated elements:
  - physical form
  - sensations/feelings
  - perceptions
  - will
  - consciousness

which disintegrate at death

- believe in **Karma** (deeds/actions). It is only the result of previous actions that ensures a new set of elements is reconstituted to create a new person
- believe in **Nirvana** – state of enlightenment and permanent liberation.

Practices:

- There is a wide variety in Buddhist belief and practice of death. The funeral is not usually viewed as a ‘religious event’.
- The coffin may be taken in a decorated carriage to the hall where the funeral takes place.
- It is surrounded by flowers and gifts, which are given to the monks after the ceremony.
- Prayers are said.
- There is music and food.
- Death and reincarnation takes one nearer to Nirvana so usually there is no display of grief or tears.
- Emphasis is on new life, not on death.
- The attitude is of calmness and acceptance of death.
- White is often worn at funerals.
- Coffin may be opened.
- A photograph is placed near the coffin to remind those present of the transient nature of life.
- The body is cremated.

CHRISTIANITY

The most common groups within Christianity are:

- Anglican/Church of England
- Roman Catholic
- Orthodox
- Protestants

Christians believe:

- in God
- in Jesus as the Son of God
- in eternal life - a quality of being
- that human beings are in continuing fellowship with God - throughout life and after death – soul goes on after life.
- in resurrection – the body is resurrected at the Day of Judgement
- in heaven/hell (some)
- in judgement
- For Roman Catholics, there is a state called purgatory - a place in which the soul of a person is purified ready to enter heaven.
- There is only one life to be lived

Practices:

- The practices associated with death re-affirm essential Christian beliefs and are a means of reaffirming faith in God - which will help to cope with the loss and sorrow.
- When a Christian dies, it is seen as the end of his/her life on earth. A funeral is held for friends and family to grieve for the person who has died and give thanks for their life.
- Burial was inherited from the Jews - but cremation is also common today
- The funeral service usually takes place within a week.
- The body is placed in a coffin and taken to a church.
- Funeral service consists of bible readings/prayers/music. The actual service structure varies according to which branch of Christianity is followed. For example, in the Roman Catholic faith there may be a Mass.
- In Protestant/Anglican rites there is a great emphasis on Hope of resurrection
- Diversity in practice e.g. Irish 'wake' – body laid in at the coffin with the lid open at dead person’s home. Family and friends will sit around the coffin, talking praying and sometimes singing.
- Wreaths: traditionally these are round to symbolise continuity and eternity
- Colour of mourning = black (until 8th Century white)
- It is acceptable to display grief with tears - this has been encouraged by the 'church' as a means of coping with loss.
- Memorial service may be held later. Memorials can be affected more by social pressures rather than beliefs, so it is not necessarily a religious event.

HUMANISM

Humanists believe:

- that death is a natural end to life
- that death should be as painless as possible, hence support for voluntary euthanasia
- that there is no 'future life' or 'heaven', punishment/reward
- that there is no supernatural dimension

Practices:

- Legally there need be no ceremony at all; the undertaker could dispose of the body. However, humanists are extremely sensitive towards the needs of the living. So there may be non-religious funeral ceremonies or memorial meetings.
- The form of the ceremony is determined by the relatives and the wishes of the deceased. Usually there is a simple ceremony at the crematorium or burial ground. This can be taken by a Humanist Official – celebrant.
- A key and distinctive element of the ceremony will be the remembrance and commemoration of the dead person's achievements in life.
- The ceremony can include music, poetry and readings.

HINDUISM

Hindus believe:

- that each person has a soul which is permanent and unchanging
- that at death the soul sheds its body and 'puts on' another body (not necessarily human) in an endless cycle of re-births. Finally it will reach God
- in the transmigration of souls
- that during life one passes through 16 stages. The stages are called SAMSKARAS
- in one God - Brahman
- that the physical body is made of Fire, Air, Earth, Water
- cremation returns the body to fire/air
- burial returns the body to earth
- that death brings impurity into the home
- in the law of KARMA (deeds) N.B. There is tremendous diversity/range within Hinduism particularly as it is affected by regional factors/practices.

Practices:

- A priest usually conducts the funeral.
- The body is wrapped in a new cloth and placed in a coffin. Sometimes gifts are included e.g. piece of gold or silver and garland of flowers/beads.
- The body is usually cremated within 24 hours of death.
- The coffin is carried to the place of cremation by 6 male relatives. Close female relatives are discouraged from attending the cremation - distress (cultural rather than religious)
- The coffin is covered with flowers. Ghee is poured over it to help it burn. The eldest son should set the coffin alight. In Britain - press button at crematorium
- Readings about reincarnation are selected from the Holy Books
- 3 days after cremation the ashes are collected and scattered on a river – River Ganges if at all possible
- Colour of mourning = white.

- Friends and relatives bring gifts to the family, keep them company, share grief and support them on 11th/ 13th day - all will gather to offer ‘Pinda’ (rice balls) and milk - to the dead person - this is to show they are grateful for the acts of kindness which they received during his/her lifetime. The eldest son or other male relative will have their head shaved as a sign of bereavement and cleansing.
- After the 13th day, public mourning ends in a large feast, after which only private, personal grief remains.
- Memory is preserved in daily worship
- Some Hindus hold feast and make donations to charities at 3,6,9 month or yearly intervals.

ISLAM

Groups within Islam:
- Sunni
- Shia
- Ahmadiyya
- Sufi
- Ishmaeli

Muslims believe:
- there is one God - Allah
- that Muhammad is the prophet of God
- that they must submit to the will of Allah
- that there is only one life to be lived
- in physical resurrection of the body
- in judgement - Paradise everlasting - no intermediate stage - Hell is strict and impartial justice
- that there will be a day of judgement - cosmic upheaval, each soul will be judged according to deeds while on earth
- that when a person dies their soul is looked after by the angel of death in a place called Barzakh (for one day) until God finally judges the world
- that death is temporary separation
- that extravagant expressions of grief are rebellion against the 'will of Allah'

Practices:
- Mourning is demonstrated by readings from the Qur'an - in this way the bereaved are supported and comforted by their faith.
- Prior to death, friends and relatives will gather and read from the Qur'an. The dying person always tries to say the Shahadah.
- Burial takes place within 24 hours. (Bury as believe in physical resurrection).
- The body is washed, perfumed and wrapped in three pieces of white cotton (shroud) - men by men and women by women.
- Coffins will not be used – unless required by law. The body will be buried with the face towards the MAKKAH.
- The grave will not be marked by a monument or tombstone
- The family (traditionally) stays indoors for 3 days after the funeral - they will not cook. Friends and relatives will bring food to them.
- The grave may be visited every Friday for 40 days.

- The mourning period will last up to 3 months. During this time there will be no celebrations or weddings.
- During EID celebrations, visits will be made to the cemetery to say prayers at family graves - this is a reminder that even in midst of happy celebrations - life is temporary and it is important to live correctly to ensure eternal life with Allah.

JUDAISM

Groups within Judaism:

- Orthodox:
    - Hassidic(Ultra-orthodox)
    - Sephardic (Mediterranean/ Middle Eastern)
    - Ashkenazi (European)
- Reform
- Liberal

Jews believe:

- in one God
- that there is only one life to be lived
- that after death the soul goes to the 'world to come' (OLAM HA'BA)
- that they should focus on what is involved in being faithful to God in this life and contributing to humanity.
- orthodox believe in resurrection of the body (cremation forbidden)
- orthodox believe in the coming of a Messiah - at which time all souls will return to their bodies
- Reform Jews use the expression of 'life eternal' for resurrection of the body (cremation permitted)

Practices:

- The key in relation to practice is to concentrate on support for the close relatives whilst ensuring that the memory of the individual is retained.
- The last words a Jew will say before death is the SHEMA. Within 24 hours the body will be ideally buried. The body will be washed, dressed and placed in a plain coffin.
- There will be no flowers - to ensure that there is no distinction between rich and poor. Mourners will cut a slit in their outer clothes as a mark of grief.
- The cemetery – Bet Hayyim- means 'house of life'. Everyone will participate in the interment by filling the grave with earth. The closest male relative will say the prayer - Kaddish - to help the dead person's soul to Olam Ha’ba.

- For one whole week the family will 'sit in mourning' - friends will provide food for them, they are encouraged to express their grief and talk about their loved one. For a month they will not participate in any entertainment. There is a gradual reduction in the intensity of the mourning in order to aid re-adjustment.
- For the following 11 months Kaddish is said every day. Mourning is for 12 months.
- Each year on the anniversary of the death the family say kaddish and burn a candle for 24 hours. The grave should be visited at least once a year – especially just before the Jewish New Year to ensure that cherished memories do not fade and to comfort the bereaved.

SIKHISM

Sikhs believe:

- in one God
- in reincarnation
- in heaven and hell - a soul may rest for a while before returning to earth. The soul will be corrected and/or rewarded. Heaven/Hell are temporary dwelling place– person's soul may be reborn several times.
- that there will be union with God - after human beings have progressed upwards through many existences from the lower forms of life. This union is descried as 'merging' with God
- that death is to be welcomed as removing the last obstacle to the complete union of God and the believer (hence do not encourage mourning).

Practices:

- Before death - friends and relatives say the Sukhmani - psalm/song of peace from the Holy Book **(Guru Granth Sahib)**
- The body is washed and dressed by friends and relatives will make gifts of money and oil. The coffin is taken to the Gurdwara. The Gurdwara is the focus for all ceremonies rather than the home.
- In the Punjab, the body would be cremated.
- Only male relatives attend the service and then they will return to the Gurdwara for readings/prayers/hymns. The service ends with the distribution of Kara Parshad (offering of food) and a feast. This to symbolise the continuity of social life as opposed to the isolation from human contacts and normal activities – also the rejection of fasting and other ritual manifestations of grief.
- The ashes of the dead body are scattered on a Holy River.
- Money is donated to charities.
- For 10 days the family will read from the Guru Granth Sahib (mourning period).
- Relatives and close friends will keep the family company, comfort them, share grief and support them.

From Harrow Psychological Services Guidance for schools and other children's services - June 2010

Schools report they have found this Practice Paper helpful and we value feedback. If you have suggestions about other information that should be included or would like to make any other comments please contact your liaison EP.

APPENDIX D – Interventions for Recovery

A printable leaflet is available on the following pages.

Interventions for Recovery

Following a crisis your child might:

- Develop a fear of the dark or be afraid of being alone
- Become clingy; have problems sleeping; want to sleep in parent's room; have toileting accidents
- Become quiet and withdrawn
- Have difficulty concentrating
- Have unexplained tantrums

How can I support my child?

If children are to overcome the effects of a crisis they need help to regain their sense of emotional safety. Parents and other trusted adults could help them do this.

Remember…

Provide lots of reassurance and comforting
Maintain regular routines such as attending nursery or school

Provide firm limits, these help to maintain a sense of security.

Correct any misunderstandings about the crisis

Protect from further fright or unnecessary separations

Provide opportunities for play

Monitor their play at home and in school

Listen to and accept their fears

Listen to and accept their strong feelings and vivid memories of the crisis

My child won't talk to me

After a crisis it is not unusual for children to keep things to themselves. Usually, this is because they do not want to upset adults. Sometimes it's because they blame themselves.

If you are worried about your child you might like to talk to someone who works with children, such as:

- Head Teacher
- Class Teacher
- Children's Support Worker
- GP
- Psychologist

Interventions for Recovery

A Guide for

Parents and Carers

of

Children/Young People

Affected by Crisis

What is a crisis?

The dictionary describes a crisis as "a time of danger or great difficulty".

Many children know about crisis through personal experience of:

- Parental separation or divorce
- Witnessing parental violence
- Death of a relative or friend
- Serious illness of a relative or friend
- Physical or sexual abuse
- Serious accidents or fire
- Bullying

How do children react to crisis?

There is no such thing as a typical reaction. Children react to crisis in different ways. Most children show changes in their behaviour.

These changes might appear immediately or not until weeks or months later. You might notice changes at home, school, or both.

Reactions are often short lived. How long they last depends on many factors including the nature of the crisis, their age, family circumstances and the support available from family and friends.

When changes appear immediately following the crisis they are easier to understand.

When the reactions appear much later their importance can easily be overlooked or misunderstood because adults do not link the change in behaviour to the crisis.

Instead, adults might come to believe that the child is just being difficult and uncooperative.

What should I look for?

If your child has been through a crisis the main things to look out for are changes in how they think, feel and behave.

Thoughts and feelings

It can be difficult to notice changes in children's thoughts and feelings especially if they can't put into words what is troubling them.

Following a crisis, children often begin to <u>think</u> and <u>feel</u> differently about themselves and others. The same is true of adults.

Following a crisis, children often:

- Think that they are responsible for the crisis; that they did something wrong; they may blame themselves.

- Feel unsafe and insecure; they may feel guilty, become easily upset by everyday events.

- Do not know why they feel the way they do and need help to talk about and understand their feelings.

Behaviour

It's easier to spot changes in your child's <u>behaviour</u>. Others may notice too – friends, relatives and your child's teacher – so it's worth asking them.

Young children often express their fears and worries through their play – so observe their play.

If your child attends nursery or school ask staff about their play.