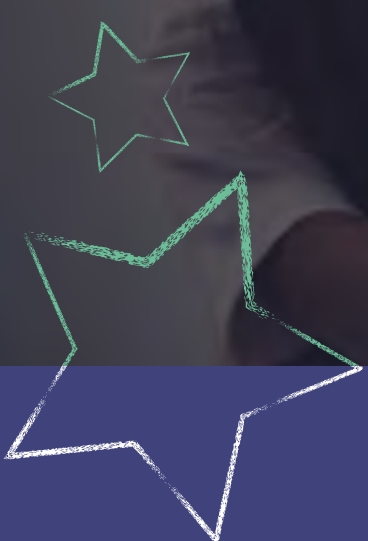




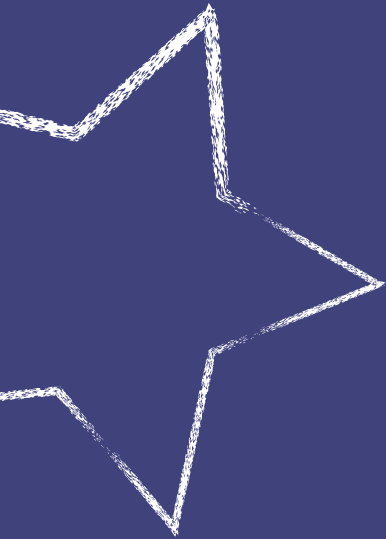
Supporting children and young people when somebody close to them is seriously ill

INFORMATION FOR PARENTS AND CARERS



Grief support for
children and young people
in Oxfordshire





SeeSaw is a small, independent Oxfordshire charity founded in 2000 to provide grief support for local children, young people and their families, or those who care for them. We provide advice, information, resources, consultation, training and support for schools and, when appropriate, face-to-face support sessions for children and young people, usually in their own homes. We offer telephone advice and resources to enable family members and professionals to provide the support. Often we help them to find the right words, or to understand that a child's reaction is very normal for their age, or how to think about the situation from a child's point of view.

Introduction

When someone has been diagnosed with a potentially terminal illness, families often ask us what they should share with their children and when. SeeSaw has supported families experiencing the impact of life-limiting illness in Oxfordshire since 2000. We work alongside families from the point of diagnosis, throughout their treatment pathway, to end of life care. Many parents tell us they feel reassured in knowing we will continue to stay alongside their family after a death.

Our role is to offer support, advice, and information around the ways that children and young people can be affected by the impact of serious illness and end of life planning, while carefully considering what information and support *they* might need themselves. We work closely with families and their children's schools to form a joined-up network of support around each family.

This booklet pulls together the most common questions we are asked and the advice we share. We are a responsive service, placing the unique needs and concerns of families at the centre of our support. We draw on knowledge and experience shared with us by many families who have faced similar challenges. We suggest that you may not want to read the whole booklet in one sitting but dip in and out of the sections most relevant to you at the time. We have also included information about other support organisations, as well as useful resources for you and your family.

This booklet is not intended as a replacement for in-person advice and support. Please see the next sections for more information about how SeeSaw can help and how you can contact us.

Judith Mulligan, Director

How can SeeSaw help?

At SeeSaw we have a team of practitioners, some of whom are dedicated to working with children and families when someone is dying. This is called a pre-bereavement team.

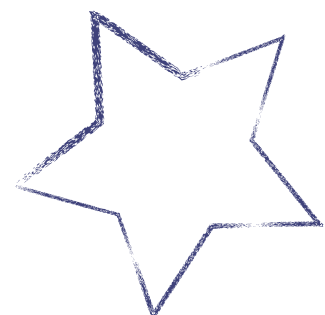
We provide a bespoke service to help parents support their children, talking through their concerns and providing advice, resources, and, where appropriate, one-to-one support for children and young people.

If you live in Oxfordshire, we can visit you in the home, hospital, or hospice. We can work directly with children wherever needed, or simply provide telephone or video call support to parents. We also regularly speak with schools and provide training where necessary.

The work we do one-to-one with young people gives them an outlet and safe space to share their worries, concerns and challenges. Our work with them helps them learn to recognise and begin to process their feelings, while at the same time developing coping strategies and support networks.

How do I contact SeeSaw?

You can contact SeeSaw by email on info@seesaw.org.uk or by following the contact link on our website. A member of staff will contact you within 24–48 hours.




SECTION 1

How can I support my child when I am, or somebody close to them is, seriously ill?

When a parent, sibling or grandparent is seriously ill, the chances are that your child will already suspect that there is something wrong before they are told. As parents and carers, we naturally want to protect our children and young people from life's challenges. In doing so, we often underestimate how much they need to know and how well they can cope with information that we feel is too sensitive or too difficult for them to hear.

The reality is that children need clear, honest, age-appropriate explanations so that they feel included in what is happening and prepared for what is to come. The alternative can be that they will search for information elsewhere or begin to believe things that are incorrect and may be more worrying for them.

We cannot prevent the many emotions that children and young people will experience at this time. But with open and honest dialogue, we can strengthen trust and reduce anxiety to ensure the support children need will be readily received and more effective.



“It helped to talk to someone who could clarify the important issues. It gave me confidence and reassurance to trust my own instincts about how best to help my children.”



Communication and what they may already understand

What you choose to share with your child will depend on their age and stage of development and on any previous experiences they may have had with serious illness. While we can offer advice and support with these conversations, you know your child best and will be able to judge their level of understanding and the most appropriate way to give them the information they need.

Young children below the age of around 5 years old will usually find it difficult to grasp the meaning of serious illness. They will probably be unable to understand, and may become frustrated by, any changes in their carer's physical and emotional wellbeing, such as reduced activity, low energy levels, or low mood. They will benefit from short, simple explanations and the opportunity to have their questions about what is happening answered. This may need to be repeated to help them take it in.

Similarly, children with specific learning difficulties or developmental disabilities *may* have limited understanding of serious illness and struggle to make sense of the changes they see. They too will benefit from brief, clear explanations using straightforward, concrete language.

Broadly speaking, children of primary school age will have some understanding of the implications of serious illness but may still have misconceptions that they will need you to correct. Asking them regularly about their understanding can help.

As children move into the teenage years, they develop the ability to reflect on serious illness and what it may mean for them and for their families, both now and in the future. They will benefit from honesty, clarity and inclusion where possible, as well as the invitation to ask questions and discuss their concerns whenever they need to.



Telling children and young people about illness, symptoms, and treatment

When speaking to children of any age and at any stage of development, we suggest that you try to avoid using euphemisms if you can. Words like 'battling' or 'fighting' may be misunderstood and can contribute to feelings of anxiety. Instead use clear, simple language, for example, 'having an operation or treatment for a serious illness'. We often speak about building a jigsaw of information, beginning with an initial conversation where children are told that somebody close to them is seriously ill and are given the name of the illness, (e.g. cancer, motor neurone disease). When speaking to younger children, and in order to prevent fears arising when they themselves are unwell, it is important to emphasise that the illness their loved one has is not the same as the common childhood illnesses they may experience.

Further information about symptoms and treatment can be added to this conversation if you feel your child is open to hearing more. One sign that a child is ready for more information is that they ask questions. However, if they seem reluctant to engage in the conversation, you could ask if they would like to know more about it now or prefer to wait. They may need a break after hearing the initial information but will often return with questions when they are ready for the answers. Further pieces of the jigsaw can be put into place in later conversations and as changes occur.

Children will benefit from being prepared for the side effects of certain treatments, such as excessive tiredness, hair loss or vomiting, with explanations, where appropriate, that these are effects of the treatment rather than signs that a person's condition is getting worse. Of course, it is possible that some of the symptoms of the illness may also overlap with treatment side effects.

As time passes, there are likely to be changes in physical symptoms, energy levels, and possibly emotional wellbeing that children will notice. They may worry about these changes if they are offered no explanation. It helps to speak



regularly and honestly with children about these changes in order to allay their fears and to build and maintain trust, while remembering to check their understanding along the way. Do not worry if your child does not want to talk about what is happening or to ask questions. This is a natural response. Just remind them regularly that they can speak to you when they are ready.

Be prepared for your child's questions. Each child will manage news of a serious illness in their own unique manner – even siblings within the same family. As you will hear along the way, there are no right or wrong emotions or reactions. Your child may have many questions about what is going to happen, or about the illness, treatment, and side effects. These questions can come at any time and are frequently raised during an unrelated activity or conversation, often when they are side by side or behind you, such as during a car journey, game, or creative project. Try to prepare yourself and keep in mind the answers you want to give and be reassured that it is ok to say that you do not know if that is the case. It may feel difficult to reassure your child when you do not have all the answers yourself, but children benefit from hearing that you will keep them updated with what is happening.

Reassurance and routine

For many children, including those who are very young or have learning disabilities or neurodevelopmental disorders, their concerns may lie in the practical aspects of what is happening here and now. They may worry about what will happen to them if a parent is in hospital, who is going to make their meals, do their hair, take them to school, or read their bedtime story.

Maintaining consistency with routines and boundaries as much as possible and ensuring children know who will take responsibility for their care will help them feel safe and, therefore, more able to regulate their emotions and continue with their day-to-day lives. As

emotional outlets, exercise and creativity will also help with this, so children should be encouraged to continue with their regular activities and spend time having fun wherever possible.

Reassurance can be given that there is no right or wrong way to feel about what is happening to their loved one. It is ok if they feel sad, angry, scared, anxious, or a mixture of many emotions. Hearing that they are free to express their feelings, that they are safe and loved, and that they will be cared for even if their parent is seriously ill, will also help them to self-regulate and to move forward.



Telling school

Children and young people spend a great deal of time in school, college, or at nursery. It is important that their teachers and carers are aware if somebody close to your child is seriously ill. This is so that they can understand any changes they may observe in your child's emotional, behavioural, or physical wellbeing and communicate this information back to you. The school, college, or nursery should also be updated when changes occur at home.

Older children and young people should be consulted about which staff and peers – if any – they want to inform. They should also be asked if they would prefer to tell school staff themselves or be supported with information sharing by another adult.

Your child may find it helpful to have a named member of staff who is aware of the situation at home and with whom they can speak if they are feeling upset or distressed during the school day.



Self-care and support networks

When thinking about support networks, it is important to consider who is part of yours and who may be part of your child's. These may overlap or be distinct from one another.

First and foremost, parents are usually the primary source of information and comfort for their children. It may help to consider the impact of caring responsibilities on the family, what could change, and how can you all still make time to connect with one another. This may mean setting aside small chunks of time to 'check in' with each other, as well as drawing on outside support.

Try not to worry if you or your child begin to feel disconnected from each other due to the time constraints treatment and caring can impose. Focus instead on planning time to reconnect over something light, such as a favourite film, bedtime story, a walk, or preparing a meal together. Talking about everyday things and making time to laugh together helps feelings of connection grow and paves the way for more serious conversations when required.

At SeeSaw, we encourage parents not to be afraid of showing their emotions to their children. Witnessing a parent's distress is not easy for children but they learn a great deal about managing big emotions by seeing a parent when they are upset, and hearing an explanation of why they are upset, before the adult continues with everyday tasks, such as going to work, driving their children to an activity, making dinner, or reading a bedtime story. From this modelling of healthy behaviours and healthy strategies, children learn that it is safe for them to express their emotions too and that their emotions will pass.

Whether you are seriously ill, or you are caring for children when somebody else is, it is essential that you also look after your own physical and emotional wellbeing. Take time out for yourself whenever you can – time to relax, continue with your hobbies and pastimes, take exercise, get some fresh air, or meet friends – and encourage your child to do the same where appropriate.

Draw on your support networks but only accept offered help that you feel you will benefit from and do not be shy to say no to the rest. For example, a friend may offer to take your child to school for you each day but this is the time when your child usually opens up to you so you would prefer to continue to do it yourself. Ask them if they would be able to support in another way instead. Keep a list of practical tasks that others could do for you so that you are prepared when asked "What can I do to help?"

Remember that we all need support at times and there are many organisations and networks that you can access for this, including contacting our team at SeeSaw.



SECTION 2

How do I tell my child that I am, or somebody close to them is, going to die?

Before you sit down to talk with your child about what might lie ahead, it is important to have taken time to consider what you and your family want from the time that is left. There may well be limitations but, with some careful thought, it is still possible to plan some special times together and find new ways to enjoy things that are important to you. Having a clear sense of your wishes can help your loved ones do something positive and practical to make your time together really living, rather than simply existing.

Being told that you are, or somebody close to you is, dying can bring a level of fear and uncertainty. You will need time to absorb and process what you have been told about the condition and your options before you consider speaking to your children. If you need extra support, you may want to talk to the healthcare team involved or the support teams within condition-related charities, such as Macmillan Cancer Support, the Motor Neurone Disease Association, or Marie Curie. You can also speak to your GP. You may want to contact our clinical team at SeeSaw or a national childhood bereavement organisation such as Child Bereavement UK.

Choosing to tell a child that somebody they love is going to die may feel like an insurmountable task that goes against all of our protective instincts. However, there are long-term benefits for children which outweigh any short-term gain of protecting them by either concealing what we know or avoiding the subject. These conversations are naturally extremely difficult but, with support and preparation, it is possible to share this information and begin to plan and prepare for what happens next.

Starting the conversation

It may seem that there is never a good time to give children sad news. However, it helps if you choose a time when you are feeling calm and have had the opportunity to prepare yourself, plan what you are about to say, and consider what you can do together afterwards. Choose a place that is private, without distractions, and where you are unlikely to be interrupted.

We would recommend, where possible, that the family are together when the children are told that someone is going to die. It is helpful that all the relevant adults involved in the care of the children know what has been said so that they are prepared for any subsequent questions or conversations. It is also beneficial that the children know there are no secrets and that they can speak to any of the adults around them if they want or need to.

We would suggest that you try to avoid talking to the children before they need to leave the house for school or an activity or just before bedtime. Allow time afterwards for questions and some family time. This models to your child that you, as a family, are able to cope with these big emotions and still return to everyday life, which is reassuring for them. Telling the children at the start of a weekend or school holiday will allow them some time to process the information before having to return to school.

It can be a good idea to start by asking the children what they already understand about what is happening and correct any misunderstandings before moving on to give any further information. If there are children of differing ages and/or stages of development in the family, try to aim the conversation at the youngest. If necessary, further information can be added in individual conversations afterwards with the older children.



Making memories

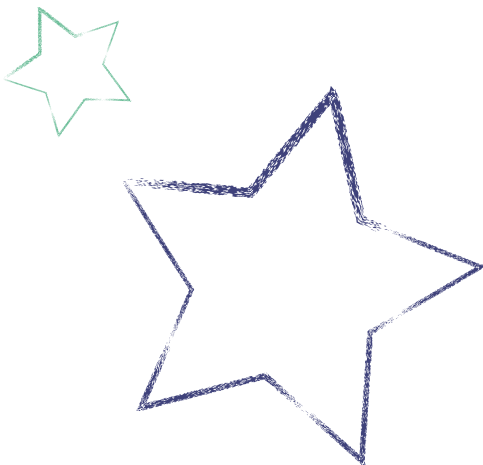
It is important for children to have memories of their loved one so that their bond with them continues after they die. Parents who know that they are not going to recover from their illness often try to carry out some memory work for their children by providing objects, letters, and recordings. The Childhood Bereavement Network's website 'Plan If' provides simple, practical ideas for all parents to plan for their family's future in case they die while their children are still young. There are also suggestions to capture family stories and write letters for the future.



Sometimes people tell us that they are struggling to do any memory work as it is such an emotionally loaded task, especially for people already trying to manage the side effects of treatment or caring responsibilities. If you are struggling, try easing the pressure by lightening the tone. Memory work does not have to be done alone by the person who is unwell. For example, sharing funny stories together over a meal, or taking time to find out more about one another as a family, can take the spotlight off the unwell person and allow them to benefit from hearing about others too. These conversations could be recorded by anyone in the family. Marie Curie has some helpful conversation starter cards you may find useful.

Here are some ways to capture important memories for children:

- memory boxes – buy or decorate a box and fill it with personal items, such as photographs, cards, a piece of jewellery or a watch, a signature perfume or aftershave, an item of clothing, or a CD of favourite music
- thought boxes – using small cards or sticky notes for each separate thought, fill a box with memories and wishes for the children, such as 'I remember when...', 'I felt proud of you when...', 'I hope that you...', 'I love you because...'
- recordings – video and audio recordings are easy ways to capture memories and allow children to see the face or hear the voice of their loved one after they have died. These can be done using a mobile phone, camera, or with apps such as 'RecordMeNow'
- family playlist – a playlist of favourite songs or songs that bring back happy memories of family times together
- photograph albums – personal photograph albums for each individual child to keep and look at when they want to remember or talk about the person who has died
- clothing – favourite clothing can be made into a cushion or teddy





Hospice, hospital, and home preparation

When facing a terminal diagnosis, there are many decisions to be made with the support of your medical team. Many parents worry about what is best for their children when making these decisions. Some think it is better for the children if their parent is cared for at home, while others believe that the children will be more protected if their parent is cared for in a hospice or hospital.

There are many things to consider when making these choices, not least the preferences of, and benefits for, the person who is dying. Some parents want to involve their children in the decision-making process. In these cases, we would suggest that you should try to have, and understand, all of the facts and options available. The first choice the children should be offered is whether they would like to be involved in these discussions, rather than expecting them to want to be involved. Try to balance the pros and cons of each option, both from the perspective of the children and of the parent. Ultimately, try not to allow a child to feel responsible for any final decisions.

Nobody can tell you what the best choice will be for you and your family. What we know is that all children will feel and react differently, even siblings within the same family, but they will all benefit from honest and open dialogue about what is happening and what to expect, whichever choice you make.

From diagnosis onwards, it is always helpful to try and see things from your child's perspective. Consider what they may notice, or how their world might be affected. They will encounter unfamiliar places, experiences, and people. Each young person will respond in their own unique way. You may be able to predict some of their reactions, yet others may be unexpected.

For example, carers coming into the family home to share nursing responsibilities can feel like a relief for the main carer. For children and adolescents, having strangers in the home can feel intrusive and they may feel they cannot relax. Factoring in young people's wishes and trying to accommodate them where possible is an important part of planning for the whole family's needs.



What questions might your child ask?

Answering your child's questions openly and honestly using clear and simple language at their developmental level of understanding will help them to process what is happening. If you do not have the answer to a question, or you find a question too difficult to discuss at that time, then it is ok to say so and follow up on it later when you have the information or feel stronger and ready to talk about it.

In our experience, these are the types of questions children usually ask:

Will I catch the illness too?

This illness is not like a cold or tummy bug and you can't catch it from them. It is ok to sit close to Daddy/Mummy/Grandpa and you can still hug and kiss them.

Who will look after me when you are/ Daddy is in hospital?

Granny/Daddy/Mummy is going to be here to stay with you while I am/Daddy is in hospital. You won't be left on your own. If you are worried about anything, you can talk to them at any time.

Who will take me to my swimming lesson/ football training/choir practice?

Granny/Daddy/ Mummy will try to make sure that you still get to go to your activities each week because it's important that you carry on with these and continue to have fun.

Is this my fault?

Nothing you said, did, or thought could ever make this happen. Just like nothing you didn't do, say, or think could ever make this happen. I am/Mummy is/Daddy is very ill and it's nobody's fault.

Are you/is Mummy/Daddy going to die?

It is important to answer this question as honestly as possible, sharing the most up-to-date information you have. For example, if they ask soon after diagnosis, death may still be a long way off and it helps to focus on what you do know rather than make long-range predictions that may be inaccurate. You might want to say something like this:



What we know is that everybody will die one day. We are listening to the doctors and doing everything we can to stay as healthy as possible for as long as possible and we will tell you when anything changes.

But as someone nears the end of life, it is important that, wherever possible, children and young people are made aware that the end is close so that they may have the opportunity to say goodbye. This conversation might start like this:

Remember when I said I would tell you if anything was changing? What we know now is that the treatment the doctors have been using is no longer working/person has become more unwell/has not got much more time to live now and will die soon.

What happens to people when they die?

When someone dies their body stops working. They no longer need food or sleep or exercise because they don't feel hunger, tiredness or the need to move anymore. They no longer need medicine because they don't feel pain. We can't see the person anymore but we can continue to think and talk about them and remember them in lots of ways.

What will happen to me when Mummy/ Daddy dies?

We will miss Mummy/Daddy very much and our lives will feel very different without them. Sometimes we will feel very sad that they aren't here with us and we will miss them. But we will get through this together.

SECTION 3

How might my child react to this news?

It is important to know that most families cope well when somebody has a serious illness. The initial shock of emotions following a terminal diagnosis sometimes leads adults to assume that their children will need professional help to get through the coming weeks, months, or years, but this is not usually the case. Families who maintain open and honest communication and who feel they are easily able to share their feelings are often surprised by their own coping skills.

As mentioned already, everybody reacts differently to the news that somebody they love is dying, so it is important to emphasise that all feelings are normal and natural responses to what is happening and there is no right or wrong way to react or behave.

Some common reactions in children and young people are:

Emotional reactions:

- sadness
- anger
- relief
- guilt
- fear
- frustration
- confusion
- shock
- anguish
- denial
- 'magical thinking'

Behavioural and physical reactions:

- acting out
- mood swings and over-sensitivity
- absentmindedness or forgetfulness
- difficulty with concentration or organisation
- regression with toileting or speech and language
- aggression
- eating less or more food than is usual
- risk-taking behaviours and testing boundaries
- disturbed sleep patterns and tiredness
- headaches
- stomach aches
- symptoms which mirror those of the dying person

“Just knowing SeeSaw were there and still are should we ever need them again is a great help and comfort.”



What may help:

- providing time to process and question what is happening
- helping children to recognise and name their emotions
- acknowledging and validating their feelings
- explaining that all of their emotions are normal and natural
- explaining that different feelings will come and go at different times
- continuing to communicate about normal, everyday life
- maintaining consistency in caregivers wherever possible
- maintaining normal routines and boundaries wherever possible
- reassuring them that they are not to blame for anything that is happening
- emphasising that nothing they think, say, or do could make things happen or change things
- teaching that everybody within the family will react differently at different times
- encouraging time to play, meet friends, and have fun
- supporting the continuation of normal activities, especially physical and creative hobbies
- introducing a list of tasks and chores that children can choose from, such as tidying, washing up, bringing drinks, or applying lotion to hands or feet of sick parent/sibling
- teaching self-regulation and coping strategies
- providing soothing blankets, toys, self-care boxes, or stories
- an understanding, flexible, and empathetic response to changes in appetite, sleep patterns, or behaviour
- remaining calm and constant and reinforcing that you are there for them no matter what and that you will share information as and when things change
- speaking with their school to ensure support is in place during the school day
- open and empathetic communication about behaviour and risk while maintaining usual boundaries
- where there are physical reactions, visiting the GP to rule out any illnesses to put your child's mind at rest

Contact your GP for advice and support if reactions are extreme or prolonged



SECTION 4

Resources and further support

- Macmillan Cancer Support
www.macmillan.org.uk
- Marie Curie
www.mariecurie.org.uk
- Motor Neurone Disease Association
www.mndassociation.org
- Child Bereavement UK
www.childbereavementuk.org
- Winston's Wish
www.winstonswish.org
- Hope Support
www.hopesupport.org.uk
- Riprap (website for older children and teens when a parent has cancer)
www.riprap.org.uk
- Plan If
www.planif.org.uk

Resources and book recommendations

Adults

- Lap of Honour: a no fear guide to living well with dying – lapofhonourbook.com/
- Marie Curie conversation starter cards – www.mariecurie.org.uk/blog/play-cards-to-spark-a-meaningful-conversation/259983

Children

- The Secret C – Julie A Stokes (Winston's Wish)
- When Someone Has a Very Serious Illness – Marge Heegaard
- The Huge Bag of Worries – Virginia Ironside
- Mummy's Lump – Gillian Forrest
- My Brother and Me – Sarah Courtauld
- When your Mum or Dad has Cancer – Ann Couldrick
- Who will do my hair? – Rachel Smith
- Who will cut the grass? – Rachel Smith
- The Invisible String – Patrice Karst
- No Matter What – Debi Gliori
- Always and Forever – Debi Gliori and Alan Durant
- Wherever You Are My Love Will Find You – Nancy Tillman

Digital resources

You Matter Most

<https://sesamestreetincommunities.org/topics/you-matter-most/>

Kooth

A free, confidential app for online support and counselling recommended by Child and Adolescent Mental Health Services (CAMHS)
www.kooth.com


Apart of me

A free app to help young people to recognise and manage a range of challenging emotions
apartofme.app


RecordMeNow

A free app to help make lasting video memories
recordmenow.org


What people tell us...




“The needs of children and young people coping with terminal illness within a family require very specific experienced help. The needs of children and siblings often go unnoticed as most of the input is often to the spouse or the parents of a dying patient. I would like to add my support for the work of SeeSaw.”




“I do not have enough words and my words are not enough to express how much we as a family unit and now myself and my son have benefited from having SeeSaw in our lives. From the bottom of our hearts... thank you.”



“Very comforting to know that such fantastic support and resources are available at the end of the phone.”



“When [she] came to visit me at Sobell House when [my husband] was dying, she somehow knew just what to say: it was as though she held me without actually holding me. She... was so calm – calming for me and for [my son]. Her visit made a massive difference to us because [my child] then felt able to come in and see his dad, when he had been scared to before. Thanks to her we now have videos of those last chats, the last game, and the last bedtime story. I hadn't told [my son] his dad was actively dying, but she gave me the confidence to have those conversations, which meant [he] then knew he wanted to be brave and see Daddy for the last time.”



“[As a school we were] able to get invaluable support from SeeSaw for the child and the rest of her family.”

Seesaw works closely with children and their families to help them learn to live in a world where someone they love is dying or has died.

We provide:

- **specialist support** for families and professionals when a parent or sibling is dying
- **telephone consultation** with any parent or professional who is concerned about a bereaved child
- **visits to families** to assess their needs and discuss how SeeSaw might be able to help
- **specially trained support workers** who can meet with the child or young person at home to help them explore the impact the bereavement is having on their lives and find ways of coping
- **group activities** that enable children and young people and families to meet together in a fun and relaxed way
- **information and training** for school staff who are supporting a child facing a bereavement or managing a death in the school community
- **training, consultancy and resources** for professionals who work with children and young people who are facing a bereavement



Grief support for
children and young people
in Oxfordshire

SeeSaw

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