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# Supporting children and young people with Autism Spectrum Disorder through bereavement



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**Abstract:** Children with Autism Spectrum Disorder (ASD) may react to a bereavement in different ways to neurotypical children. This article explores some of the underlying perceptual and processing difficulties observed in children with ASD that may affect their understanding of death and their reaction to a bereavement. But children with ASD, like any others, need their grief both recognised and understood, and will need opportunities to express how they feel. The article gives some suggestions which may help children with ASD, and includes a list of helpful resources.

**Keywords:** ASD, autism, special needs, children

## Introduction

### *'Simon took no notice and continued to play with his lego'*

Children with Autism Spectrum Disorder (ASD) can appear to behave in unpredictable ways and can respond to bereavement in ways others find difficult to understand. This can lead to the misperception that they are not affected by the death of someone close and are not grieving. At Child Bereavement UK we are often asked how best to support children with ASD and whether the methods we use for other children are appropriate. However, there are very few studies of the bereavement needs of adults with ASD (Allison, 1992; Rawlins, 2000), no studies in the literature examining the bereavement needs of children with ASD to help us understand what they are experiencing, and scant resources to guide our support. In fact the wider special needs literature suggests that western society has a history of failing to understand the bereavement needs of those with special needs in general (Blackman, 2003) despite more recent studies demonstrating that individuals with special needs experience bereavement and grief in a manner similar to the general population (McRitchie *et al*, 2013).

A systematic review of the literature by Dodd, Dowling & Hollins (2005) showed that whilst bereaved people with

intellectual disabilities may experience similar emotions such as sadness, distress and anxiety, the way this manifests behaviourally may be different. McRitchie *et al* (2013) suggest that people with special needs are more likely to experience greater complications with grief due to higher levels of secondary loss, communication difficulties and issues around inclusion. There is also much evidence to suggest that those with special needs are often not even informed about the death of someone significant to them and may be excluded from rituals such as seeing the body, attending services or visiting the grave (Forrester-Jones, 2013).

## What is ASD?

Terminology has changed over the past few years and can be confusing. This article therefore uses the term Autism Spectrum Disorder which reflects current opinion that autism is a spectrum condition, in that all those with autism share certain difficulties.

Autism Spectrum Disorder (ASD) is characterised by qualitative differences and impairments in reciprocal social interaction and social communication, combined with restricted interests and rigid and repetitive behaviours (NICE, 2011). ASD is estimated to affect 1% of the population (Baxter *et al*, 2014; Brugha *et al*, 2011) and is frequently associated with co-morbid

difficulties with mood, anxiety, and emotional and behavioural problems (Moseley *et al*, 2011; Maskey *et al*, 2013). Children with ASD can present their parents and carers with many challenges and it is recognised that carers of those with ASD experience a greater degree of stress and depression (Firth & Dryer, 2013). Children with ASD sometimes exhibit behaviours that the rest of society may find difficult to understand and many parents report feelings of isolation (Woodgate *et al*, 2008). Therefore families in which there is a child with ASD can be considered more vulnerable than average.

Whilst we can apply the usual principles of grief and bereavement to those with ASD, our understanding is limited unless we are also able to comprehend the way that such children experience the world. If we can begin to figure out how the cognitive differences underpin the observed symptoms, we can begin to work out how best to help when the added stress of a bereavement occurs. Therefore, it is crucial to examine the underlying perceptual and processing difficulties giving rise to the behaviour we observe in children with ASD.

## Mindblindness

***'I had to prepare Jenny for the fact that no-one would clap her when she played the piano at her grandmother's funeral'***

In order to behave appropriately and interact with others in socially acceptable ways we must be able to work out what other people are thinking and feeling so that we can predict and explain other people's behaviour. This ability is referred to in the literature as having a 'theory of mind'. One of the most widely accepted neurocognitive models of ASD is the suggestion that those with ASD have a fundamental difficulty with theory of mind, that they demonstrate 'mind-blindness'. There is now a large literature supporting this view that many of the difficulties in social behaviour seen in children with ASD are due to the difficulties they have in representing the contents of both their own and other people's minds (Baron-Cohen, 1995). In recent years this model has been extended to include the role of empathy, showing that the capacity to emotionally respond to others' mental states appropriately is also impaired (Baron-Cohen, 2002). Thus the model now includes both cognitive and affective aspects, explaining that those with ASD have difficulty in both identifying other people's mental states (beliefs, feelings and intentions) and also in responding emotionally to them in appropriate ways (Chakrabarti & Baron-Cohen, 2006).

Keeping in mind that the environment, both physical and emotional, following a bereavement may be very different to usual, let's consider how a difficulty with theory of mind might impact on a child's behaviour and understanding of events.

- The child may fail to comprehend how others are thinking and feeling, and therefore have difficulty in understanding how other people are behaving.

- The child may fail to understand the ways in which other people may be able to help them.
- The child may have a lack of understanding of how their own behaviour might be perceived by others and the impact of this on both other people and themselves.

## Getting the gist

***'All Micky was interested in at the crematorium was how hot the oven was going to be and what it would do to Nana's body.....he didn't seem interested in how I was feeling about it all'***

It is very widely recognised that a key information processing difficulty in children with ASD is that of information integration – the ability to simultaneously make sense of many pieces of information and put it all together to make a coherent whole. In other words, they frequently fail to 'get the gist', or to understand the relationships between events and ideas, tending to focus on parts of an image or story rather than the overall picture (Barnes & Baron-Cohen, 2012). Sometimes referred to as 'the drive for central coherence', it is this ability that allows us to identify certain information as important, and integrate that information from our sensory experiences to make sense of what is happening around us in the social world and to form a coherent understanding of the whole. This focusing on single aspects can lead to a difficulty in generalising and therefore in being able to apply learning from one situation to another.

How might difficulties in assimilating and integrating information affect a child's understanding and behaviour surrounding a bereavement?

- The child may have difficulties in attending to all the different bits of information and putting it together. Neurotypical children will be able to infer that someone is unwell when they see that person in hospital with tubes in their arms and machines to help them breathe. Children with ASD are much less able to draw the intuitive conclusions that others make unless those connections are made explicit.
- Problems understanding aspects of rituals – eg. what to do and not do during hospital visits, or during church services or the funeral etc.
- The child may focus on one particular aspect to the exclusion of other relevant information eg. the flowers on top of the coffin, the cars people arrive in at a funeral, what happens in a cremation, rather than the social meaning of the event.
- A child with ASD who has experienced death in one situation may not be able to apply that learning to subsequent experiences other than in a rigid format eg. if someone dies in a hospital, the child may lack the understanding that death does not happen to everyone who is ill in hospital, or may think that the only way people die is in hospital.

## Language and communication

### ***'Sammy can't enjoy her birthday any more as it signifies she is another year older and growing up . . . and I told her that I wouldn't die until she was all grown up . . . '***

Difficulties with communication are associated with ASD (Howlin, 2003; Miniscalco, 2006; for diagnostic criteria see DSMV and ICD-10 (American Psychiatric Association, 2013; World Health Organization, 2014)) and most children with ASD will have problems with some aspect of language. This varies widely from one individual child to another and can range from a complete absence of functional verbalisation to very subtle difficulties in the social use of language. Sometimes a child may present with a good vocabulary and seemingly good comprehension. However, it is easy to be distracted by the use of correct terminology and we must always check out a child's understanding of events. Most neurotypical children make good use of the context of language to work out what people around them mean by particular terms and this is something that children with ASD can find very difficult to do. A child with ASD is more likely to interpret a word in the way they last experienced it rather than accounting for the situation in which it occurs. Children with ASD respond best when we use very concrete language. There is a general taboo in society in talking about death and we frequently use euphemisms rather than using terminology such as 'dead' and 'dying' – a recent internet search identified over 50 different euphemisms! This is often difficult for neurotypical children who are better at extrapolating meaning from a situation, and for a child with ASD it can be extremely confusing.

Children with ASD are also much more likely to have difficulty deciphering the meaning of non-verbal communication which is heavily dependent on context. Whilst they may be able to recognise tears as indicating sadness they will be less able to infer sadness from more subtle indications, or contextual clues eg. someone talking about the person who has died.

How might these language difficulties impact a child with ASD with regard to bereavement?

- The child may have difficulties understanding what is going on around them unless others are very explicit in explaining it, and use very concrete terms. This can be a challenge to the adults around them who may feel uncomfortable about using words such as 'dying' and 'dead' around children.
- The child may have difficulties finding out what is going on – eg. in knowing what questions to ask, who to ask and when it is appropriate to ask.
- Children with ASD are commonly very literal in their use of language and this can be problematic for those around them. Other people who are unfamiliar with the child may have difficulty in managing the child's 'matter-of-fact' attitude or repetitive questioning.
- The child may have difficulty understanding other people's emotions. Much of what we express about our feelings is non-verbally communicated, so children with ASD frequently

have great problems recognising their own and others' feelings and emotional behaviour.

- Social situations can therefore make children with ASD very anxious – as they find it difficult to decide what to do and say and find other people's behaviour unpredictable. This can also make their parents and carers anxious too. In a bereavement situation when emotions are running high this can be particularly difficult to manage.
- The child is likely to take things very literally eg. if told 'the funeral is a happy event to celebrate his life,' do not be surprised if the child then laughs aloud and treats it as a party. The child may have little understanding of the impact of their behaviour on others around them and how they will be interpreting their behaviour.
- Seeming indifference to a death is not an inability to feel emotions but a logical lack of connectivity to others emotions. For example, the response of a child to the death of a baby sibling may be a logical one, such as 'have another baby then,' which may come across as an insensitivity to others' feelings.

## Preoccupations

### ***'Over the next few days Leo became obsessed with death and asked continual questions'***

Children with ASD frequently exhibit very narrow and intense interests such as street signs, aeroplane flight paths or particular films. Whilst the focus of the interest is not fixed and may change over time, at any one time it can be so focused that it excludes other interests or activities. The child will seek to find out as much as they can about their particular interest and may ask repeated questions of the adults around them. At times of stress and upset these preoccupations, which often serve a role in reducing anxiety, may increase. Whilst this can be problematic, it can also be capitalised on by providing fertile ground for the development of strategies which can help the individual with ASD to calm themselves.

How might such preoccupations be problematic regarding bereavement?

If the focus of a child's interest is a death, this can be felt to be 'morbid' or unnatural. Society's difficulty in being open about death and dying makes it harder for the adults around the child to see this as a simple manifestation of the child's need to make sense of what is happening by repeated questioning and searching for facts. The more allusive our responses, by the use of euphemisms, unclear language and failing to answer questions directly and honestly, the more difficulty the child will have in understanding what is happening and the greater the curiosity.

Children with ASD can become preoccupied with particular routines and can become extremely anxious when events do not go as predicted. Change is therefore especially difficult for children with ASD to cope with. They find it hard to predict other's behaviours and may retreat into behaviours and preoccupations that are familiar. When there is a bereavement in the family

everyone is affected and everyone's behaviour will change but there may also be many resultant practical changes eg. to the daily routine; to the people who are carrying out particular roles such as doing the school run, making the packed lunch or taking them to football club; to the emotional environment of the home; and these may even extend to house moves and financial changes. Thus the secondary losses in terms of the loss of the familiar following a death can be widespread and are felt particularly keenly by children with ASD, which in turn can lead to a rise in anxiety, anger and challenging behaviour.

## Imagination and time perception

### ***'Sacha just couldn't understand what heaven was'***

Many children with ASD have difficulty with imagination. Being able to imagine something relies not just on memory and the ability to call to mind something that is not present, but also requires us to think about possibilities, and create alternative scenarios. The ability to consider hypothetical events, such as what might happen in the future, relies on this capability. This means that children with ASD can have problems in understanding abstract concepts such as heaven and the soul and tend to be very literal in their usage and understanding of language, failing to account for contextual factors. It also leads to a difficulty in understanding the unspoken and unwritten social rules which neurotypical children appear to learn through inherent extraction of the rules through social experience.

Children with ASD tend to predict future events based on specifics of past events without extracting the underlying social rules and can rigidly adhere to details so that if events stray even in a small way this can cause great distress. For example, for a child with ASD 'going shopping' may mean a trip to the supermarket and if told they are going shopping will expect it to be the same shop the next time. Thus if told they are going shopping and they then find themselves in a bookstore, this can cause much distress. It is thought that this difficulty in imagining how things might stray from the expected may underlie the anxiety that many children with ASD have surrounding change.

A related difficulty that many children with ASD experience is in processing the passage of time. Partly due to their difficulty in imagining the future, children with ASD tend to be much more 'in the moment' than other children. This can lead to difficulty in understanding how sequences of events are organised in the future eg. what happens when.

These perceptual and processing idiosyncrasies may lead to difficulties around bereavement in several areas:

- The child may have difficulties predicting what may happen next. Neurotypical children are able to infer future likelihoods eg. if they see a person becoming more and more unwell over time they are likely to question whether that person is likely to die (even if they don't voice it!). Children with ASD are less likely to consider this possibility due to their

difficulties in conceptualising the hypothetical. The child with ASD is much more likely to focus on the here and now and the changes that might be happening to them at the time.

- The child may have difficulty anticipating the impact of the loss from a death eg. changes to routines, and how things might be different in the future.
- The child may have difficulty understanding the abstract terminology used by the adults around them.
- The child may fail to understand consequent implications of the death eg. that because someone has died means they will not be there tomorrow, or next week, or next month, or next year. Similarly, that the person is no longer around to visit on Sundays, attend birthday parties, or come to stay during the summer holiday.
- It can therefore be difficult to prepare a child with ASD for future possibilities, especially in situations where there is much uncertainty eg. when someone has a life-limiting or life-threatening condition.
- Children with ASD are much happier dealing with facts and certainties. This is challenging for the adults around them who may feel a need to protect the child and therefore avoid certain topics.
- The child may not intuitively understand that it would be inappropriate and insensitive to crack jokes during a funeral service.

## Sensory issues

### ***'Amir pushed me away and wouldn't let me give him a hug . . . he took to carting around his mum's cardi and now he wraps it round him, rubbing the soft wool against his cheek . . .'***

Children with ASD frequently have a number of sensory issues, including hyper or hyposensitivity and particular textural preferences. This may be related to their difficulties in 'getting the gist' leading to a tendency to focus on a single sensory experience rather than the overall situation and to their difficulties with imagination leading to a greater interest in more concrete, sensory perceptions. Thus a child with ASD may focus specifically on the look, sound or feel of something or find particular sensory situations especially challenging.

These sensory sensitivities might manifest in a number of ways in a bereavement situation:

- Rituals surrounding death may involve unusual sensory experiences eg. smells from perfume, after shave, floral tributes or sounds echoing around a church/village hall.
- As texture is often an issue, a child with ASD may feel very uncomfortable having to wear particular items of clothing that the event requires eg. wearing a suit or a dress for a funeral or ceremony.
- Environmental characteristics may trigger anxiety and distress eg. lighting and acoustics in a hospital ward.

- Children with ASD are less likely to seek physical comfort from other people and may find it difficult to handle others' behaviours. Behaviours that encourage physical closeness, such as hugging or kissing, are often associated with the giving of reassurance but children with ASD can be particularly sensitive to human contact and may find these different expressions and expectations hard to manage.

## Grief and ASD

Children with ASD may have specific problems in conceptualising death and the rituals that surround it, as a result of their information processing difficulties and problems in understanding hypothetical events. But, just like other children, they will need their grief both recognised and understood and will need opportunities to express how they feel.

Before we can consider how to best help children with ASD in their grief, it is helpful to look at an accepted model of grief with respect to the challenges faced by children with ASD. William Worden's (2008) model of grief suggests that there are four tasks which must be accomplished during the mourning period in order for 'equilibrium to be re-established'.

Whilst this is not a sequential, linear model as each task may well be revisited over time and individuals will be idiosyncratic in their achievement of different tasks, there is an extent to which some tasks are dependent upon completion of others:

- To accept the reality of the loss
- To work through the pain and grief
- To adjust to a new environment in which the deceased is no longer present
- To find an enduring connection with the deceased whilst moving forward with life

Taking each in turn, we will see that all four of these tasks are more challenging to achieve for children with ASD through a combination of the child's processing difficulties and the problems we have as adults in recognising these difficulties and in accounting for them.

**Accepting the reality of the loss** – this is made so much more difficult if incorrect terminology is used, if questions are not given honest, timely and accurate responses, and if your conceptual understanding of events is different to those of others. If you are prevented from seeing the person after they have died, or from attending the social rituals surrounding a death such as the funeral, cremation or memorial service, again this makes achievement of this task more challenging. Children with ASD need to be given informed choices about participating in such proceedings and not shielded by misguided attempts to protect them. This is likely to entail much consideration of the adults surrounding the child and addressing what assistance they might need in best supporting the child.

**To work through the pain and grief** – As discussed above, children with ASD have a much greater difficulty accessing and recognising emotion. It can also be difficult for those around them to manage the seeming lack of expressed emotion that children with ASD frequently display. Due to the nature of their communication difficulties there may be less opportunity for a child with ASD to discuss their loss with family or friends, and adults may assume they are not grieving. The intense emotional environment that may follow a death, may lead to a heightened and continual sense of anxiety that can be exacerbated by the implicit societal expectations surrounding a death. Many unwritten and unspoken rules surround grief, regarding how to behave and what might help, and for a child with ASD these need to be overtly identified and addressed. It has been suggested that before a child with ASD can process the emotion surrounding a death they need to understand in a very factual way what has happened (Lipsky, 2013). Neurotypical children, when in a supportive and encouraging environment, generally wish to share their grief with others, and to seek reassurance and solace from those around them. In contrast, children with ASD are frequently much more solitary in their grief and may be more likely to seek comfort from isolation. This may be a withdrawal from the heightened emotional context or overwhelming sensory overload, or an attempt to process the confusing emotions and behaviours of those around them.

**To adjust to a new environment in which the deceased is no longer present** – the changes that occur as a result of a death, in family life, the environment and the emotional atmosphere, serve to exacerbate uncertainty and lack of predictability. This is hard enough for neurotypical children to adapt to but can be extremely challenging for a child with ASD who already finds the world a capricious and uncertain place. This highlights the importance of giving honest and accurate information to the child at a degree appropriate to their level of understanding. As Lipsky, herself on the Autistic spectrum, writes in her book about supporting bereaved people with ASD: *'I needed a script to deal with the aftermath of his death but found no template'* (Lipsky, 2013).

**To find an enduring connection with the deceased whilst moving forward with life** – earlier suggestions that the dead should be forgotten and the living should 'move on' are now outdated and the value of remembering in longer term acceptance of the death is widely acknowledged. Opportunities to remember the deceased are generally encouraged through recollection of positive past events and promotion of 'bringing the deceased into the present and future' through memory activities. This is in stark contrast to previous views which rather encouraged the bereaved to 'leave the deceased behind them'. However, memory work techniques that we might use for neurotypical children in encouraging them to keep this connection with the deceased may or may not be helpful, depending upon the

individual. Children with ASD's tendency to live in the here and now and difficulties with processing emotional information may mean that there is a delay in the usefulness of memory work. It may be best left until such a time as the child has dealt with and understood some of the more practical and factual issues surrounding the death.

## What can you do to support a bereaved child with ASD

### *'Rosie's reaction was immediate and she wailed for several minutes before calming down'*

The following suggestions may help when supporting a bereaved child with ASD.

- As with other children, a very individual approach by someone who knows the child well is best.
- Manage your own expectations and do not expect a child with ASD to demonstrate their grief in the same way as other children.
- Try to keep to the familiar, keeping to as many normal routines as possible. Any additional changes are likely to create more distress.
- Expect that the child may seek solace through isolation rather than social contact.
- Expect a general increased sensitivity eg. the child may be quicker to anger than usual or sensory sensitivities may be amplified.
- Give the child the opportunity to take part in social rituals but be ready to put in a lot of preparation beforehand (eg. social stories, see below). It may be helpful if they are able to have something to actually do, such as hand out the order of service, pass round refreshments etc.
- Be explicit about events and rituals and address the hidden social rules directly.
- Do not be afraid of an interest in seeking 'the facts' surrounding a death and try to answer questions openly and honestly and give information using accurate and concrete terminology.
- Avoid euphemisms as children with ASD will have even more of difficulty extracting meaning from them than other children.
- Expect a rise in pre-existing self stimulatory behaviours (eg. rocking, tapping, flicking) or special interests, both of which can have a calming influence.
- Prepare others for how the child might behave and explain they are not being purposefully rude or unfeeling and will be experiencing grief but may be expressing it differently.
- Know the child's individualities and sensitivities and try to work out what may be most difficult for them and try to address it (eg. maybe the lighting in a hospital room, attending a funeral and seeing others cry, or worrying about who will take them to school now).
- Ensure that the child's usual methods of self-soothing are available at times particularly likely to precipitate distress, anger or anxiety.
- Prepare the child for events and for changes in routine wherever possible.

**Social stories** can help prepare a child for events, such as an expected death or for changes to routines. Using clear, accurate language and visual images (it is best if these can include photographs and also involve the child) to create a personalised account of facts and events, they can help explain other people's behaviours (such as why people are quiet during a church service) and people's thoughts and feelings. The National Autistic Society website (see box, p101) gives a very helpful example of how a social story was written to support a child whose father had a terminal illness. Social stories can help a child learn about death and other related aspects outside the emotionally charged atmosphere that may ensue following a bereavement, so that some aspects are already familiar. Social stories are an aid for both increasing social understanding and identifying appropriate behaviours and can easily be used to prepare for social rituals such as funerals, cremations and memorial services.

**Use visual and physical examples** to illustrate what being dead means and to explain the irreversibility of death in a way appropriate to the child's understanding. Try to take a biological approach that is practical, clear, and visual and capitalise on examples from nature with concrete examples eg. comparing a dead fish with a live fish, observing flowers wilting and dying.

**Prepare for participation** in social events such as church services by visiting where it will happen, taking photographs or making a video tour. Plan in advance management tactics, for example identifying who will do what and when and also have an exit strategy planned in case events do not go as predicted.

**Visual aids** can help prepare a child for proceedings, explain death/rituals surrounding death and plan/catalogue events. They can also help with understanding timelines, sequences of events and changes to routine. One child whose mother had died found it helpful to have a picture timetable that included a photograph of his mother with a line through it. This reminded him that she would no longer be there when he returned home from school and helped him to prepare emotionally for it. Calendars and charts can help prepare for hospital visits and put significant events into a wider context.

**Multisensory memory boxes** – put together a multisensory memory box of tangible reminders chosen by the child. This can help give some insight into factors and events that are key to the child's relationship with the dead person. Try to keep in mind the importance of concrete reminders of the person who has died and try to include something relating to all five senses. A memory box therefore might include pictures of the person and pictures

of things that person enjoyed, a small object that belonged to the deceased person, a piece of fabric that is associated with that person (that may have a particular 'feel' to it), a CD of music that the person enjoyed or recording of them speaking, something that reminds the child of the smell of that person (perfume, aftershave, toothpaste, deodorant etc). Be aware that the child may not be ready to participate in memory work until much later.

**Listening** to audio recordings of the voice or favourite music of the dead person may be familiar and comforting

**Comic strip conversations** – these are a tool used to aid verbal language in explaining social situations. Supplementing the spoken word with drawing and writing, they aim to help make explicit social rules, other's likely thoughts, feelings and behaviour and thereby increase understanding. Using the 'comic strip conversations' technique can help others understand what a child is thinking and feeling and can provide the opportunity to discuss things that the child might otherwise find difficult. This strategy can help identify misunderstandings and highlight emotions that have perhaps not been overtly expressed or that have manifest in other ways. You can find out more about how to do this from the National Autistic Society website (see box, p101).

**Emotional Literacy** – help the child learn how to recognise different feelings and emotions in themselves and others as well as learning appropriate ways of expressing their feelings. You can do this by using everyday situations and events to point out different emotions in other people (eg. on TV programmes, in magazines and stories) by using consistent and 'simple language to label emotions from the child's own experiences and by using pictures. Using images is particularly helpful for children with ASD and a 'feelings thermometer' can help a child express the intensity of an emotion. You can do this by drawing a picture of a thermometer with a rating scale up the side. Encourage the child to show where they are on the scale to rate the strength of their anger/sadness/worry. Similarly, using the analogy of a volcano to illustrate anger and how it sometimes 'boils over' can be helpful, both through drawings and making models.

## Conclusion

The ideas outlined in this article are in no way meant to replace the techniques that we would ordinarily use in supporting bereaved children, but are to be seen as an adjunct to them, additions to our toolkit from which to select approaches that might be suitable for any given child. Children, like adults, will grieve in their own individual way and this is just as true for children with ASD. However, having an understanding of how a child might be experiencing the world around them can help us more fully understand how they might be grieving. We can then consider the needs of each particular child within more general models of bereavement and grief and consider what steps we need to take to best provide the support that they as an individual might need. ■

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## Useful resources

**Autism and loss** by Rachel Forrester-Jones and Sarah Broadhurst (2007). A complete resource including fact sheets and practical tools suitable for use with adults and children. Published by Jessica Kingsley [www.jkp.com](http://www.jkp.com)

**Books beyond words:** A series of books without text, based on simple images. <http://booksbeyondwords.co.uk/bookshop/>

- *When dad died* by S Hollins, L Sireling and B Webb
- *When mum died* by S Hollins and L Sireling
- *When somebody dies* by S Hollins, S Dowling and N Blackman

**Comic strip conversations.** For a guide on how to use these see **National Autistic Society** [www.autism.org.uk/About/Strategies/Social-stories-comic-strips](http://www.autism.org.uk/About/Strategies/Social-stories-comic-strips)

**Death, bereavement and Autism Spectrum Disorders.** Information available from the National Autistic Society Information Centre. [www.autism.org.uk/bereavement](http://www.autism.org.uk/bereavement)

**Finding your own way to grieve** by Karla Helbert (2013). Published by Jessica Kingsley, London and Philadelphia. A practical and creative activity workbook for children and young people on the autism spectrum.

**Hand in hand:** Supporting children and young people who have a learning difficulty through the experience of bereavement. A resource pack with practical ideas including a section on using symbols to explain death and funerals. Published by SeeSaw. [www.seesaw.org.uk](http://www.seesaw.org.uk)

**How people with autism grieve and how to help: an insider handbook** by Deborah Lipsky (2013). Published by Jessica Kingsley, London and Philadelphia. Provides a personal account of the author's own experience of bereavement.

**National Autistic Society** [www.autism.org.uk](http://www.autism.org.uk)

**SAD** by Lucy Finch - A beautifully designed creative resource, including a story, emotion stickers and a pot of memories. Only available direct from the creator. [www.behance.net/gallery/4126443/Autism-Bereavement](http://www.behance.net/gallery/4126443/Autism-Bereavement)

**Social stories** - For further details on how to write a social story visit The National Autistic Society: [www.autism.org.uk/Living-with-autism/Strategies-and-approaches/Social-stories-and-comic-strip-conversations.aspx](http://www.autism.org.uk/Living-with-autism/Strategies-and-approaches/Social-stories-and-comic-strip-conversations.aspx)

**Support for the bereaved and the dying: a guide for managers and staff in services for adults on the autism spectrum** by Helen Green Allison. Revised in 2014 and available through the National Autistic Society. [www.autism.org.uk/products/core-nas-publications/support-for-the-bereaved-and-the-dying.aspx](http://www.autism.org.uk/products/core-nas-publications/support-for-the-bereaved-and-the-dying.aspx)

**Understanding death and illness and what they teach about life: an interactive guide for individuals with autism or Asperger's and their loved ones** by C Faherty and GB Mesibov (2008). EDS Publications Limited. Aimed at individuals with ASD, presents information about death in a clear and concrete way, seeking to make explicit information about what happens when someone dies and other people's likely responses to it.

For further general information on Autism Spectrum Disorders:

**How to live with autism and Asperger Syndrome: practical strategies for parents and professionals** (2004) by C Williams and B Wright. Published by Jessica Kingsley.