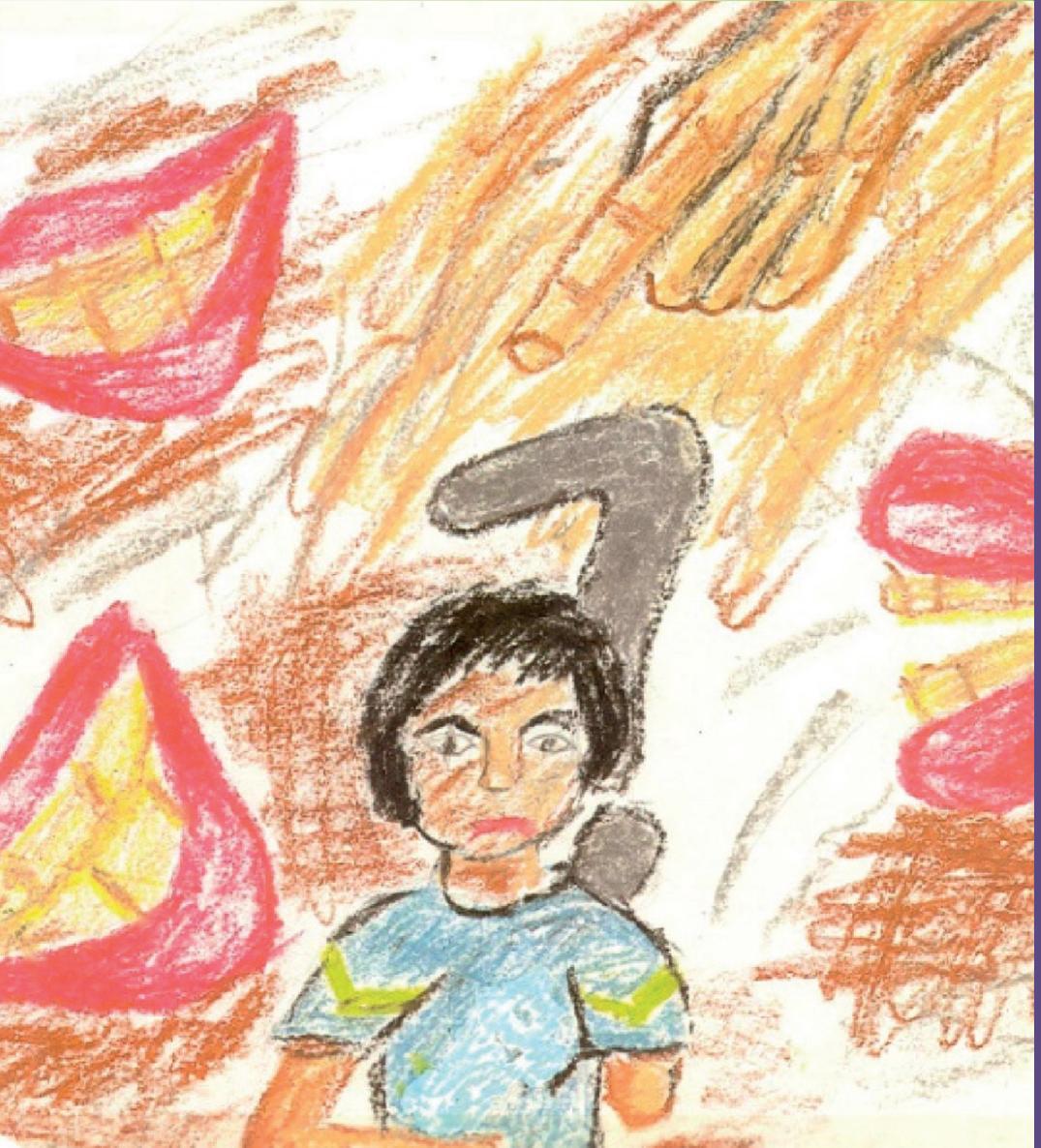


Emotions

Helping children and young people with a life limiting condition and a learning disability to understand and cope with their emotions



Introduction

For anyone, receiving news that they have a life-limiting condition can be both a shocking and traumatic experience. It's hard enough to imagine it for yourself, but for children and young people with a learning disability, the world can suddenly become a confusing and frightening place.

Supporting children and young people who struggle to express or perhaps even understand what this means for them, is a challenge for any professional. Emotional regulation is a process which facilitates coping with provocative or anxious situations to lessen the stress of negative emotions (Cicchetti, Ackerman, & Izard, 1995) and may not function for this group of children in the same way as it does for others.

When breaking difficult news, with the parents' consent, use gentle conversations and don't be afraid to use clear language to explain what is happening. Draw pictures, be prepared to give small amounts of information and repeat it many times.

Children with a learning disability respond to information in unexpected ways. It is common to get no reaction at the time and then have

questions later. Such ambivalent reactions suggest that children do not understand what they have been told or lead us to believe that they don't care.

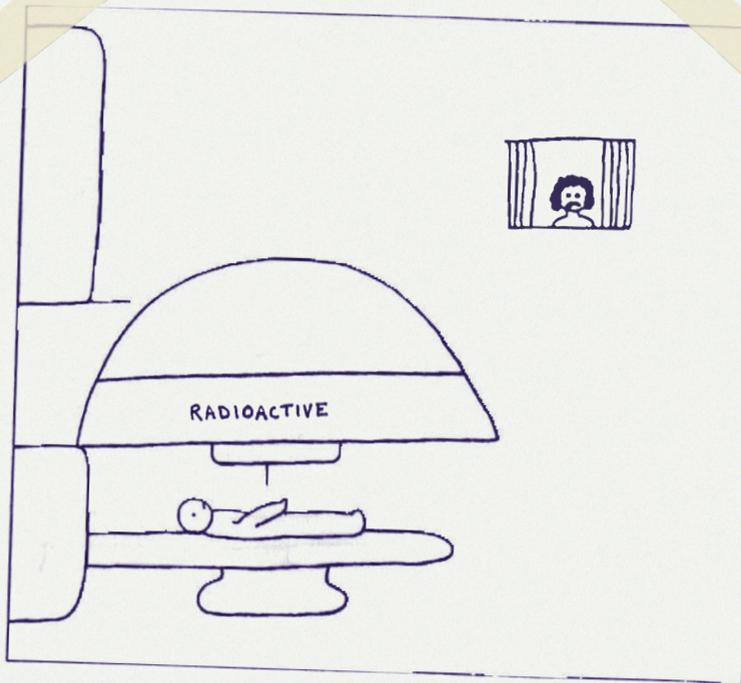
Encourage children and young people to express how they feel verbally, using pictures, drama, drawing and painting, or physically by screaming in the shower. Emotional expression is OK as long as it's expressed in socially acceptable ways that don't impinge on other people's safety. The ARCH model (Read 2009) provides a useful framework when delivering bad news, and can be found within the palliative care leaflets within this Toolkit.

Intellectual disability is not the same as emotional disability. Children with a learning disability may have limited verbal communication, yet are often capable of letting us know how they feel. The responsibility lies with the professional to find creative means to enable the child to express these emotions in a meaningful way. Always ask the child and their parents which way they like to communicate.

Children with a learning disability often know that something bad has happened or that people are upset, but they don't know why as they have been shielded or protected from the truth.

In the absence of real facts, children sometimes come up with their own ideas which may be even more upsetting for them. Try to be honest whenever possible. Don't be afraid to talk about difficult or upsetting things, but offer an 'invitation to talk' using the many resources in this Toolkit to support you. It is OK for children to get upset and for them to see parents, brothers or sisters get upset too.





The Grandma was frightened too

Children with a learning disability may understand things more easily if they can hear, touch, see and smell things, so use tangible objects and concrete ideas whenever possible. Always use clear language and avoid euphemisms. Phrases such as “passed away” or “gone to see the angels” are not clear, are open to misinterpretation and may easily confuse children.

Ways of supporting emotional expression

We can help children and young people with a learning disability to explore and express their feelings in a number of ways.

Emotional regulation is the ability to express a range of emotions and to react in appropriate ways in various emotionally provocative situations. Children exhibiting emotional regulation skills usually adjust well to new people and situations; show a high tolerance for frustration; control their negative emotions; and consider the needs and preferences of others.

Young children who have difficulties with emotional regulation may portray few emotions, show signs of depression, cry excessively, have difficulty coping, worry excessively, or engage in inappropriate behaviours in response to intense emotions (Wittmer, Doll, & Strain, 1996).

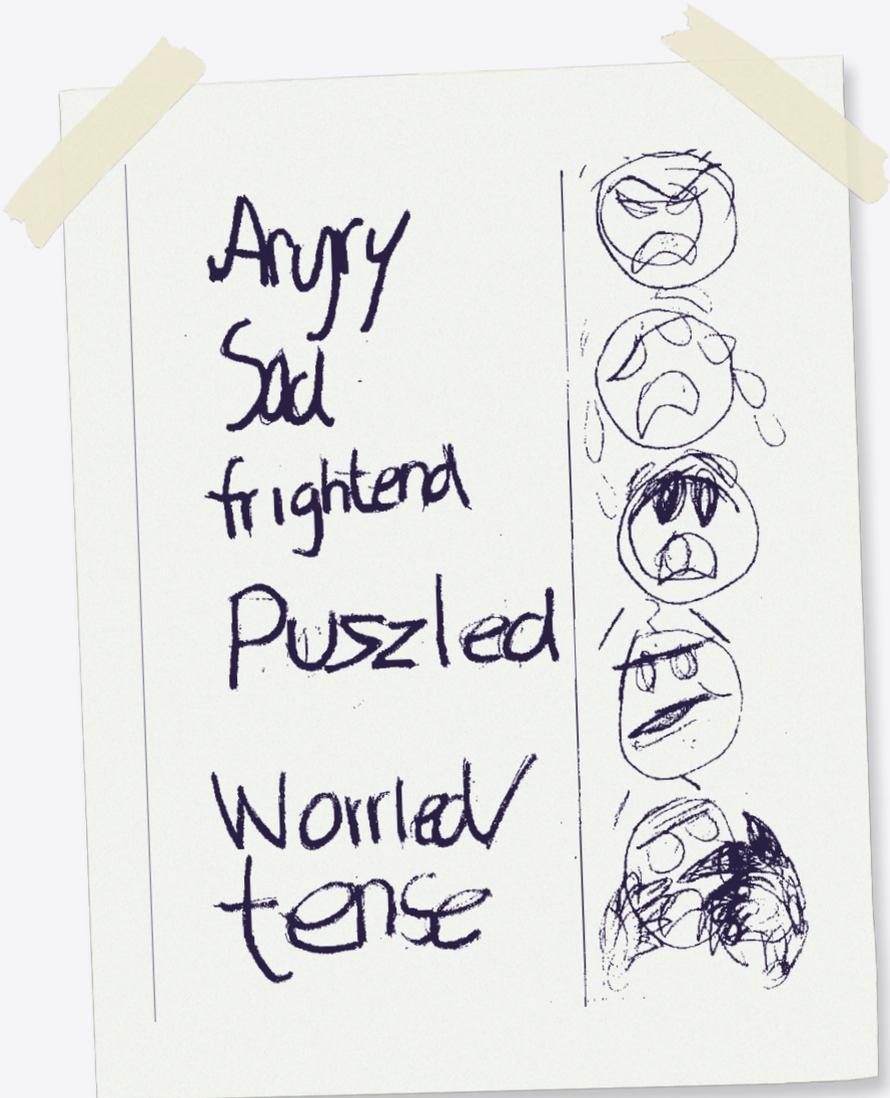
Children who internalise behaviour problems are often characterised by social withdrawal, isolation, fearfulness, depression, dependence and anxiety. Externalising behaviour problems are characterised by outbursts of emotional expression including anger, aggression, selfishness, and oppositional behaviours (Fox, 1994).



*The hurt of the pain inside
me splits my heart in two*

Emotional self-awareness Emotional self-awareness (i.e. recognising feelings, building and using a vocabulary for them) is an essential foundation for emotional literacy. All children need support in building a feeling vocabulary. Children with a learning disability have a more limited vocabulary of feeling words than their typically developing peers (Feldman, McGee, Mann, & Strain, 1993).

Consequently, professionals need to communicate clearly and consistently whilst recognising that key words or symbols (such as feeling sad or using sad faces) might represent a range of similar but different feelings (like unhappy, sad, fed up, lonely etc).

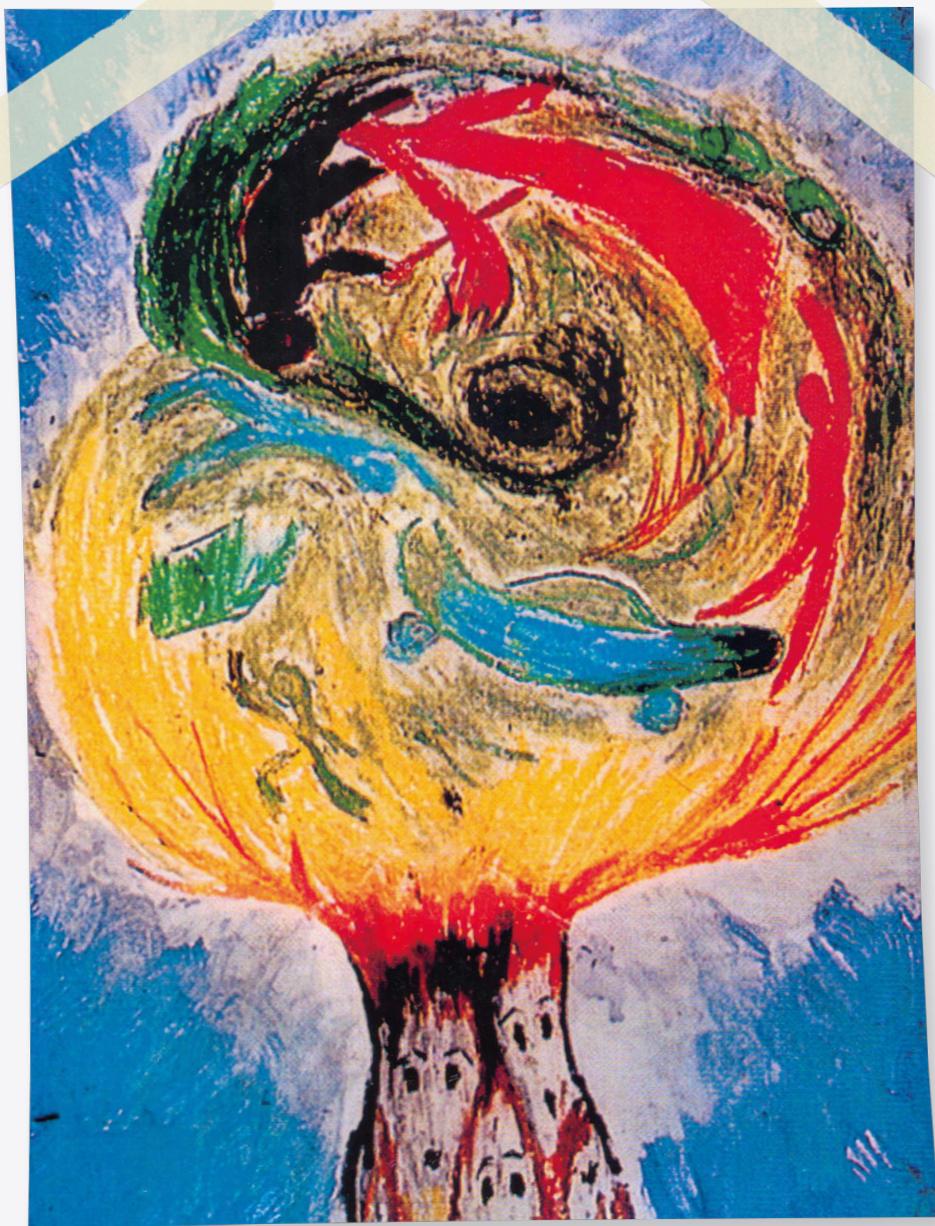


Emotions such as anxiety or anger may become further complicated by the presence of other emotions like sadness or guilt at times of loss. Parents may recognise obvious or subtle differences between the ways their children react emotionally and are often a guiding source of support for helping children to deal with their emotions.

Separation anxiety is developmentally the first specific emotion, it serves as a reminder of the fundamental link between emotions and relationships (Agulston, Hurry & Warwick 2000) and remains a timely reminder of the experiences of children who are in hospital or away from a parent for the first time, dealing not only with illness but separation too.

“It is important to provide an environment that children feel safe in, bearing in mind it may take some time for children to trust and feel safe enough to attempt to communicate innermost thoughts, fears and other feelings.”

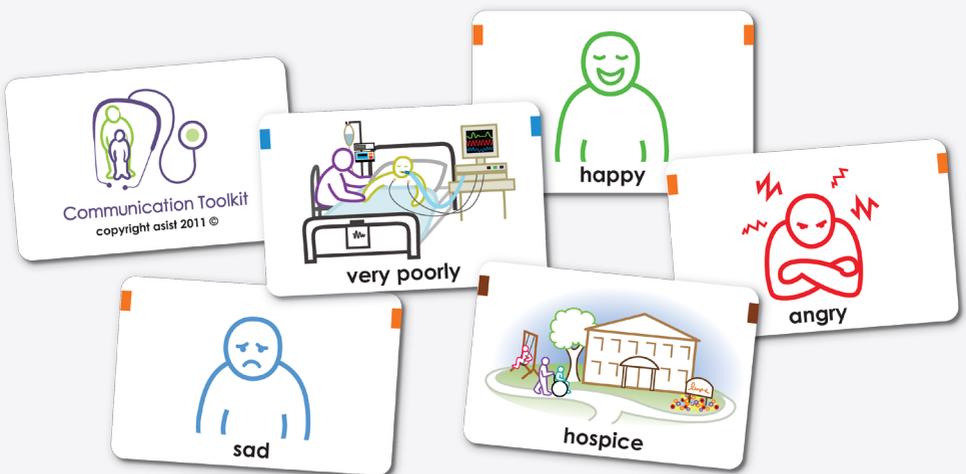
(S.K. Adams, J. Baronberg, 2005)



Things to think about:

- Name and describe emotions as children experience them.
- Observe children's facial expressions, tone of voice, and body language to assess their feelings.
- Use affective reflections (e.g. "Matthew, you are very quiet and are not looking at me today. You seem sad"). Such affirmative and non judgemental statements help the child to feel understood and accepted (Kostelnik, Whiren, Soderman, Stein, & Gregory, 2002).
- Be creative, try using the Communication Cue Cards in the Toolkit. Pair one with a corresponding emotive word/situation. By correctly labelling and acknowledging emotions, you have taken the first step in helping the child to develop their emotional vocabulary. Gradually add emotion words to expand a child's emotional vocabulary. The rating scale that accompanies the cue cards can help the child or young person to measure their emotions as they change over time.

Try using the cue cards in the toolkit. Pair one with a corresponding emotive word/situation. You may, (depending on the child's ability) introduce a variety of feeling words, beginning with the primary emotions (happy, sad, and afraid) and gradually add words to expand a child's emotional vocabulary (scared, nervous, stressed, confused, depressed, lonely etc.) Remember you can adapt the cards using the pens supplied. By correctly labelling and acknowledging emotions, you have taken the first step in helping the child to develop their emotional vocabulary. The rating scale that accompanies the cue cards can be used to help the child or young person to measure their emotions as they change over time.



So now you know a little more about emotions, we need to consider how professionals can help the child or young person to cope with their emotions. There are a range of strategies that might help.

Strategies that might help

There are a range of strategies that can be helpful when supporting children and young people to explore and express their emotions.

Music Therapy

When sad or remembering unhappy events like bereavement, listening to music can help us to preserve memories, or to feel close to that person. Many scholars (e.g. Levitin, 2007) believe our love of music starts inside the womb, where surrounded by amniotic fluid, the foetus hears sounds. It hears the mother's heartbeat, and other music, conversations, and environmental noises. Music and sounds may help children with a learning disability to cope with stressful situations and associated feelings.

In various countries, within and across cultures, music has always been a way of communicating. For many children and young people, music can anchor onto the feelings experienced at the time to somehow ground them in that moment or create an acceptance of the current situation. Talk with parents and other familiar people to find out about the child's preferences. You will always discover that there is some form of music or songs the child enjoys or is familiar with.

Play Therapy

Play has been recognised as important since the time of Plato (429-347 B.C.) who reportedly observed, “you can discover more about a person in an hour of play than in a year of conversation.” In his book, *The Education of Man* (1903), Fröbel emphasised the importance of symbolism in play. He observed, “play is the highest development in childhood, for it alone is the free expression of what is in the child’s soul.... children’s play is not mere sport. It is full of meaning and import.”

No matter how unwell, children and young people never totally lose their curiosity and capacity for exploration and will still enjoy playing, even if only in short concentrated and spontaneous sessions. There are many games that help children express emotions such as ‘The Mad, sad glad’ game (Peak potential, inc.) or ‘Feel good faces’, Feel good friends co. (2006). Explore the internet or talk to professionals for ideas on specific tools available.

Touch and massage

Touch is a fundamental and basic instinct. One of the most instinctual things is to hold hands when someone is feeling low or down about something. Hand holding anchors us into that person’s emotions and offers reassurance. Whilst gentle hand massage can be soothing for some children

it can be annoying to others, particularly children with autism who may not tolerate even the slightest touch, but can cope with deep pressure massage. Offer your hand and see if it is taken. From there, you may be able to move on to simple massage.

Aromatherapy is a form of alternative medicine that involves essential oils and other aromatic compounds for the purpose of altering a person's mind, mood, cognitive function or health. Lavender gives an olfactory sensory experience to aid relaxation.

There are myths that children with autism or learning disability do not feel pain. Whilst it is true that some children have a higher pain threshold than others, many children with a learning disability have additional sensory impairments which can make it extremely uncomfortable to be touched. Stroking hair, holding hands, cutting nails, or brushing teeth may be very distressing to some children. Always ask the child and their parents about this.

Try to ensure that the child is physically relaxed before starting invasive procedures which involve touch. Talk the child through what will happen in the procedure, using resources in the Toolkit.

Remember that relaxed muscles will make such procedures less painful and distressing. Some children are able to learn basic relaxation techniques to help them to minimise their anxiety. Use visual cues and lots of practice to help them feel confident with this. NB Professionals should be aware of the policy regarding the use of complementary therapies pertaining to their particular clinical area.

Behaviours that challenge

Behaviours and emotions that present a challenge to families or services will evoke different types of response according to:

- the way the child behaves
- the physical and social impact of these behaviours at home and elsewhere
- the meaning given to the behaviour by those caring for the child

Adults often make important decisions for young children, but rarely ask them to choose how they would like things to be. It can feel reassuring (and sometimes easier) to do the same for children and young people who have a learning disability, especially if it's hard to be sure what their views

are, or to be clear about whether they are able to think through what's best and make informed choices. Whatever our fears, young people themselves are the ones most likely to know what they like and don't like, and how a problem affects them. Professionals need to actively listen and use all available skills and resources.

The **Key Message** and **Key Information** cards suggest ways of effectively communicating. Similarly, you might find the **'Everyone Communicates'** booklet in the Toolkit useful.



Top Tips for effective emotional facilitation

- **Listen** to what a child or young person wants from their life. Work together to record young people's wishes at the centre of their care plan.
- **Help** children and young people to believe that they and their views matter. Don't just think it, say it out loud, and say it out loud often.
- **Build opportunities** for everyday choices, as making important decisions can be difficult without practice of making smaller ones. Remember that too much choice can be overwhelming.
- **Encourage** children and young people to make decisions as a family as some decisions have far-reaching consequences.
- **Make time** for decisions as children and young people rarely make decisions that they are happy with if they feel rushed.
- **Unpack worries.** Give young people strategies to deal with their worries and build in safeguards to deal with yours. Try a 'worry box' using pictures of familiar people, things etc that they want to discuss.

- **Information is power.** Young people need to know about their rights, about the options that are available to them and about preparing for death.
- **Reflect** back what you think the child or young person is telling you, to check you have understood them clearly.
- **Ensure** options aren't presented in a way that may lead to a choice just to please others. It's not just what is said but how it's said that matters.
- **Be patient** and resist the urge to rush and fill silences. If you are unsure what the child or young person means acknowledge this and start again.

Remember, think about using photographs, drawings, film and audio tapes as well as observation to capture and record feelings and any wishes they may have, you can always re-visit them when the child or young person needs to express themselves to you or others. Children with learning disabilities are children first of all. Children like to laugh, play, be cuddled, be silly and have fun. Always use the child's or young person's name, smile and include them in all conversations. Don't speak about children or young people as if they are not there.

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