

Supporting someone who is caring for a dying child

This information sheet is for when someone you know, maybe a family member or a friend, is caring for a child who is dying. You may never have needed to support someone in this difficult situation and you may feel unsure about what to say, what to do, whether to make contact or how best to help them. The fact that you are reading this information sheet shows that you care. This often is the most important step in helping someone in this situation.

Understanding what they are going through

The experience of caring for a dying child may vary depending on the child's illness, the length of time that the child has been sick and the prospect or hope of improvement or cure. Caring for a dying child is exhausting both physically and mentally. The parent/carer frequently feels overwhelmed and emotionally drained because living with grief and uncertainty often leaves them stressed and feeling powerless. There are other additional factors which may influence how the parent/carer is feeling and coping. The parent/carer may be juggling employment issues, financial concerns, other family and friends and home duties. Some parents/carers have friends but may not have anyone who is truly available to support them during times of hardship. Sadly for some parents/carers, this may not be the first time they have cared for their dying child or someone else close to them. Many parents/carers find their spiritual, cultural or religious beliefs helpful during this difficult time however, the choice is personal and individual.

How can you help?

There is no one right way to support someone who is caring for a dying child and as confusing as it may be, what might be helpful today, might not help tomorrow. The parent/carer is often sleep deprived, overloaded by medical jargon and may feel that no one else understands what they are truly going through. Sadly they are right, no one knows, because for every child and parent/carer, the experience is uniquely their own. Some parents/carers want privacy while others prefer company. Some parents/carers want to tell you what they are going through, while others may make you feel like they are shutting you out. It is important to understand that there is a great diversity in how people react at this time.

Understanding your own feelings

How you communicate with the parent/carer of the dying child will be influenced by the following aspects of your own life experience:

- If you also have a child of a similar age, you may find talking with them too overwhelming

- If someone close to you has died, this situation may bring back distressing memories and emotions for you
- If you know someone else who has been in a similar situation and feel that you can offer advice or
- You feel that you lack the experience and therefore potentially it is best that you don't contact them at all

Being self-aware of our emotions or intentions is helpful. While it is okay to be upset in front of the parent/carer, it is important that you do not add to their burden. Likewise, wanting to help them by suggesting alternative treatment options or telling them about someone else who had a similar condition and recovered is generally not helpful at this time.

How to help

Parents/carers who have been in this situation suggest the following ways to be helpful:

- Make contact – just do it! Send a text, write a card, phone but do not be upset if you do not receive a response. It is best not to have an expectation, because this is about them. Often the parent/carer will appreciate that you have made contact but may not have the energy to reply. Don't let their lack of response prevent you from leaving further messages (but don't bombard them)
- Explain that you are concerned for them and their child
- Ask about their child but don't pry - allow the parent/carer to tell you as much or as little as they want to
- Offer support – be specific if possible. If you know the person well, you might be able to suggest different ways to help. For example, offer to pick up other siblings from school, cook meals (some communities set up a meal roster for the family or donate funds for meal deliveries), buy some groceries, offer to help with laundry or household work. You can also offer to take the family dog for a walk or attend to other pet care needs.

It is important to:

- Be present, listen
- Think before you speak
- Avoid clichés
- Be patient and persist. Mostly, parents/carers appreciate the on-going support even if they do not acknowledge it
- Ask if they would like to hear about your life e.g. the school, work, other family members (some parents/carers feel isolated and want to hear about the world away from their child)
- Offer to visit but negotiate a time that suits the parent/carer
- Continue to invite them and their family to events, even if they often can't attend due to the demands of caring for their child
- Offer to be a point of communication to others in the community
- Be mindful of what is told to you by the parent/carer. It is best to determine how much information they would like you to share with other family and friends
- Maintain privacy and consider what has been told to others e.g. if the unwell child's siblings do not know the full extent of the child's illness, be careful not to reveal this information to them or their friends

Practical ways to help when you are visiting the hospital

- Ask if there is anything they want to be brought into the hospital e.g. fruit, coffee, snacks
- Do not go to the hospital if you or someone you have recently been in contact with is unwell
- Prior to visiting, determine if the ward has visiting hours, rules such as how many can visit at a time or if you are allowed to bring children
- Be prepared for things you may not have anticipated. For example, the child's condition may change or worsen or their parent/carer may be having a particularly difficult day
- Offer to sit with the child while the parent/carer has a shower
- Read a book to the child.

