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IRELAND'S CHILDREN'S HOSPICE


Reflections on how to support a family of a child with life-shortening illness

Dr Aidan McKiernan,
Senior Clinical Psychologist



Background


A resource adapted for use in paediatric palliative care



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Tips on How to Support a Family of a Child with Life-limiting Illness

FOREWORD
The suggestions or reflections described in this short resource are based on material produced by Dr Paul D'Alton, Head & Clinical Lead of the Department of Psycho-oncology at St. Vincent's University Hospital on behalf of the Psychological Society of Ireland. Warm thanks are also owed to the families and team in LauraLynn, particularly Rosaleen Maguire, Social Worker, and Amanda Kenny (our talented designer!), and to Dr Jan Aldridge, Consultant Clinical Psychologist at Martin House Children's Hospice for their considered and insightful contributions to this adapted resource. May those who chose to respond with an open heart to families of a child with life-limiting illness find assurance and guidance in these pages.



Dr Aidan McKernan, Clinical Psychologist

- 1. Being 'positive' doesn't always help**
Trying too hard to be positive can end up making people miserable! Facing up to uncertainty and insecurity takes courage and may be painful but it can be a much more helpful way to support a family as they manage the ups and down of caring for a child with complex needs.
- 2. Don't be afraid to say 'I don't know what to say'**
Learn to tolerate your own emotional discomfort. Learn to be silent and to just be there. Each family will respond in their own unique way. Try to understand what it might be like to be in their shoes by simply listening and allowing them to express what they're feeling even if it doesn't always make sense or seem logical.
- 3. Don't expect emotions to progress along in neat stages**
This experience will unfold as a process and there will be many ups and downs where their needs change on a day-to-day (or sometimes hour-to-hour) basis.



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1. Being 'positive' doesn't always help

Trying too hard to be positive can end up making people miserable.



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2. 'I don't know'

Learn to tolerate your own emotional discomfort.



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3. Don't expect emotions to progress along in neat stages

Families move in and out of grief from moment to moment.

4. Acknowledging rather than advising

Giving advice can be unhelpful and can make people feel like they should be 'doing a better job' at coping.



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5. Try not to personalise

Many families desperately want connection and support but don't know how to ask for it or accept it.



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6. Eat well, exercise and get enough sleep

Stress can disrupt our routines at a time when it is more important than ever to maintain the basics of eating well, exercising and sleep.



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7. It's important to know your own limits

Letting others help you in your supportive role and acknowledging what you can't do will take the pressure off.



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8. Be practical

Sometimes it is more helpful to offer practical support than it is to ask in an open way how you can be of help.

9. Follow the family's lead

Invite members of the family to share their experiences with you if they wish but respect too their right not to talk about all that is on their mind at a given time.



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10. Be compassionate.

Know that you cannot nor should you attempt to 'take away' a family's pain.



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Thank you.

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