



**PalliativeCare**  
AUSTRALIAN CAPITAL TERRITORY

# CHILDREN'S PALLIATIVE CARE

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## TOOLKIT



**A TOOLKIT FOR FAMILY AND FRIENDS**



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## DISCLAIMER

The content of this toolkit is intended to provide a summary and overview of the subject matter. It is not intended to be fully comprehensive. Nor does it constitute legal advice. All care is taken to provide current information however currency cannot be guaranteed. You should seek legal or other professional advice before acting or relying on the content.

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# FOREWORD



With the right resources, knowledge, and support, we can help children and families facing serious illnesses to live their lives to the fullest, with dignity and respect.

Paediatric palliative care is for infants, children and young people and it involves a diverse range of conditions, symptoms, and experiences. Paediatric palliative care acknowledges these differences and provides individualised, holistic care that is focused on the physical, emotional, social, cultural, and spiritual needs of the child and their family.

Palliative care is an approach that focuses on providing comfort, relief of pain, and symptom management to children with serious illnesses and support for their families. It is a unique approach that requires special skills, compassion, and sensitivity.

This toolkit provides insights, knowledge, and practical tools for those close to a family caring for a child with a life-limiting illness.

When a child is in palliative care, it can be a challenging and emotional time for both the child and their family. These are some of the important considerations for people close to a family with a child in palliative care:

- Respect the family's privacy: it is important to respect the family's privacy and not share any personal information without their permission. Let the family know that you're available to support them but also respect their need for space and privacy.
- Listen and offer support: listen to the family's needs and offer support in any way you can. This can include practical help such as preparing meals or helping with household tasks, as well as emotional support such as listening and offering words of comfort.

- Be sensitive to the family's emotions: understand that the family may be going through a range of emotions including sadness, anger, and anxiety. Be sensitive to these emotions and offer support without judgment.
- Consider the child's needs: if you're visiting the child, be mindful of their needs and comfort. Ask the family if there are any specific needs or preferences for the child's care and follow their instructions.
- Be available: offer to be available to the family at any time, whether it's to provide support or simply to listen. Let them know that they can reach out to you whenever they need to.
- Offer practical help: there may be practical tasks that the family needs help with, such as grocery shopping, picking up medications, or driving the child to appointments. Offer to help with these tasks if you're able to.
- Show empathy and compassion: show empathy and compassion towards the family. This can go a long way in helping them feel supported and cared for during this difficult time.

With the right resources, knowledge, and support, we can help children and families facing serious illnesses to live their lives to the fullest, with dignity and respect. I hope that this publication will serve as a valuable resource and inspire readers to support families in the best way they can.

Dr. Louise Mayo, AM  
President

# INTRODUCTION

Children's palliative care can be defined as care for families of infants, young children and adolescents who have been diagnosed with a 'life-limiting condition.'

The focus of children's palliative care is quality of life, encompassing the physical, spiritual, psychosocial elements of the child or young person and family. Other areas of health care may be focusing on treating the life-limiting condition or prolonging an end to someone's life, whereas palliative care focuses

on the quality of someone's life. Many families are supported by palliative care whilst they undertake treatments to attempt to prolong life.

When children are underneath a palliative care 'umbrella' they can be cared for by many different members of the healthcare team (such as doctors, nurses, physiotherapists, occupational therapists, and social workers), and care is delivered not only to the child, but also to the whole family.

## LIFE-LIMITING CONDITION

A condition, illness or disease that reduces a person's life expectancy.

## THE PALLIATIVE CARE TEAM

The team involves a range of supporting health professionals to create individualised care. These professionals can include doctors (specialists and GPs), nurses, physiotherapists, psychologists, occupational therapists, dietitians, social workers, pastoral care.

## PAEDIATRIC PALLIATIVE CARE

This type of care includes a diverse range of resources and information that focuses on the physical, emotional, social, financial, cultural, and spiritual needs of the child and family.





# MYTHS VS FACTS:

## **Myth: Palliative care is just for my Nanna**

**Fact:** Palliative care is for anyone who, regardless of their age, has a life-limiting condition.

## **Myth: Palliative care only happens in a hospital or hospice**

**Fact:** Palliative care starts when a family is ready for it to begin. It is a supportive process, and many families can receive care at home.

## **Myth: Palliative care only focuses on pain and management of pain**

**Fact:** Pain management and reducing pain is an important focus in palliative care, but there are so many more things that palliative care can do and help with – examples are found in this toolkit.

## **Myth: Palliative care is end of life care**

**Fact:** End of life care is an important part of palliative care, but they are not the same. Palliative care looks at improving a person's life in any way that helps to achieve the best possible quality of life for children and their families.

## **Myth: Children are too young to understand palliative care**

**Fact:** Many children understand the world around them, even if they cannot put this into words. Starting conversations early ensures that children are not afraid of the unknown. Conversation also allows children to understand why so many new people, such as healthcare professionals, are suddenly a part of their life. The palliative care team is guided by parents/guardians who know their children best.



# FIRST STAGE: WORST NEWS EVER

## Introducing palliative care

When a child is diagnosed with a life-limiting condition, it's not easy on anyone. The child and the family can undergo a tremendous amount of shock – there can be a multitude of appointments, treatments, and procedures to consider. Life as they knew it has been turned upside down, with many of the family's hopes and dreams substantially changed. This will also be the case for those close to the family.

The diagnosis of a condition, illness or disease can bring with it a variety of emotions. But when faced with a life-limiting condition, there may be a finite number of resources and treatments available. It could also mean that no matter what the medical team achieve, the condition will not be treatable and will remain life limiting.

For some families, the first stage of palliative care brings hope and acceptance – they have been fighting for their child's life for many years by now and the focus shifts from quantity of life to quality of life. For other families, where involvement of the palliative care team occurs at the same time as the diagnosis of a life-limiting condition, there can be a lot of fear. Fear of the unknown and concern that palliative care means end of life care.

The introduction of the palliative care team does not necessarily mean end of life care. At times this is true, but at other times, the palliative care team is involved earlier to ensure there is a focus on quality of life for the child and their family.



## HELPFUL HINTS

The first thing to know is that it's okay to not be okay. When palliative care is first mentioned, our instinct is to assume that end of life care has begun. Palliative care is more than end of life care. When diagnosed with a terminal condition, it can be very difficult to predict a child's life expectancy without fully understanding their life-limiting condition. The focus at this time shouldn't be on the end of life care they may eventually receive, but focusing instead on supporting the child, the family, and your contribution to that support, which is all part of palliative care.

### Tips section

Some families have found that the following strategies have been supportive when their child has been diagnosed with a life-limiting condition, consider which seem useful for you:

- Acknowledge and validate feelings – for yourself, the child, and the family.
- Don't ask how long they have to live – remember that the introduction of palliative care is not the same as end-of-life care.
- Be a support person who people can turn to talk to – some family members may need to vent their feelings and emotions about the situation. They may feel waves of sadness, anger, frustration, and hopelessness. All feelings are valid and the best thing you can do is listen.
- Offer to be there when needed – being a friend or family member that the child and family can lean on is often necessary to help them get through this difficult time.

### Be a Presence, not an Absence!

- Many people become uncomfortable when hard topics like palliative care and end of life care start being discussed.
- Often, people do this because they don't know what to say, and they worry they will say the wrong thing. So instead of saying something, people say nothing and slowly step back from their family, believing that unless they have the exact right words, it is better to say nothing.
- To be a supportive person, just be present. Ask people how you can help – there are suggestions included as Task Vouchers at the end of this toolkit. Just because you feel uncomfortable with the situation doesn't mean you need to leave it – the family can't leave it and they are likely to need your help. If, at times, you find it difficult take a step back, but try to step back in before too long.





# SECOND STAGE: SURVIVING AND THRIVING

## Palliative care when active treatment is still happening

In many instances, the palliative care team is brought into a child's health care team while they are still undergoing active treatment for their life-limiting condition. This is because palliative care is about focusing on quality of life; the palliative care team may look at ways to ease the burden of care on families, improve the child's energy levels and reduce pain.

Surviving with a life-limiting condition is not all about pain management, healthcare appointments, and bed rest. Children and young people with life-limiting conditions are still children and can thrive with your help. When children are continuing to undergo active treatment, we can often forget that they are still children with a zest and curiosity for life. They may still want to go to school, see their friends, have outings, and celebrate every moment and milestone.

Younger people with a life-limiting condition may crave a normal teenage life. It is important to recognise and acknowledge their wishes and work with the family to achieve this. For older adolescents, they may be aware and knowledgeable of their life-limiting condition and the eventual deterioration that they face. It is important that they have a space to clearly communicate how they feel and be involved in their own healthcare decision-making. Young people who crave more control over their lives may find it difficult when people make assumptions about what they can or cannot do; this can cause feelings of distress, anger, and mistrust.

For younger children, they may recognise the treatments or procedures they are undergoing for their life-limiting condition, however they may not understand the seriousness/severity of the situation. Communicating with their families is very important – sometimes families may exclude certain information from their young children, as that knowledge may cause unnecessary fear and worry. It is important to ask the family what has been discussed or what should not be mentioned, as some families may instead choose to limit a child's knowledge to reduce fear and stress.



## HELPFUL HINTS

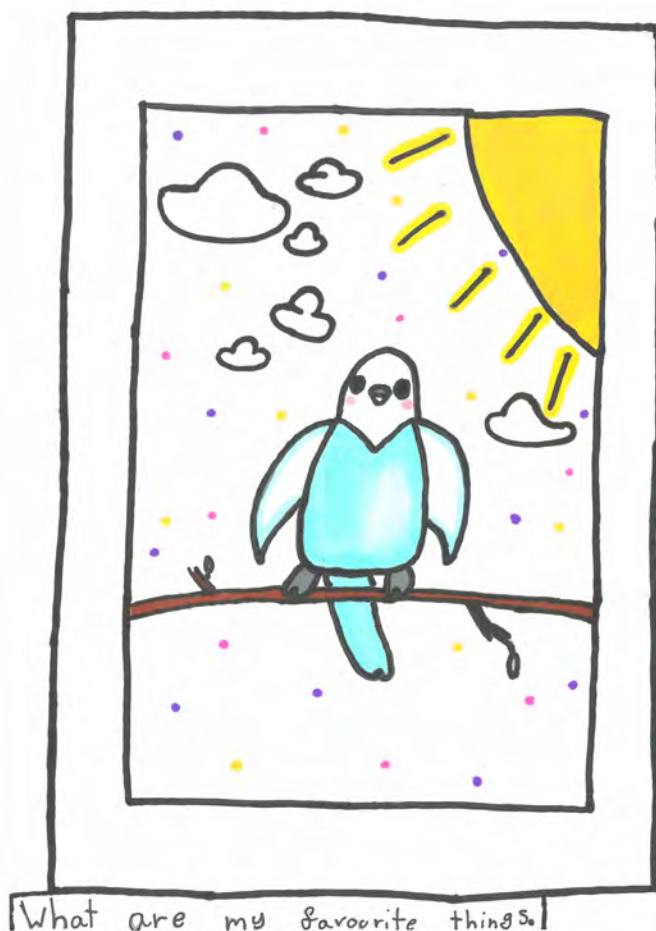
It can be difficult to ascertain the level of knowledge a child knows about their own life-limiting condition and how much detail is shared with them and others. These decisions about information sharing, are made by the parents/guardians of the child and it is important to respect these decisions. Parents of a child with a life-limiting condition have many hard decisions to make and will need to make these in a way that suits their own child and the needs of their family. It is important to remember that parents are the experts of their own children – they know them better than anyone else.

### Tips section

- Give people space to talk to you about their experiences, problems, and fears.

- Remember the best thing to do when talking about difficult situations is to be there to listen, not to solve! So many times, when people are struggling with an issue, we instinctively want to fix or solve their problem, instead of being a sounding board and listening first. Always ask people if they need help figuring out solutions to their problems, or if they just need someone to talk to.
- This is likely to be a long journey for the family – go on it with them, through the highs and the lows. The most valuable thing you can do is to be present and consistent.

Remember when it comes to Surviving and Thriving, we want to focus on the child's quality of life. Creating warm and happy memories for them and their family will go a long way to ease the burden of their life-limiting condition. Ideas for memory making are listed on pages 15 - 16.



# THIRD STAGE: NOT LONG NOW

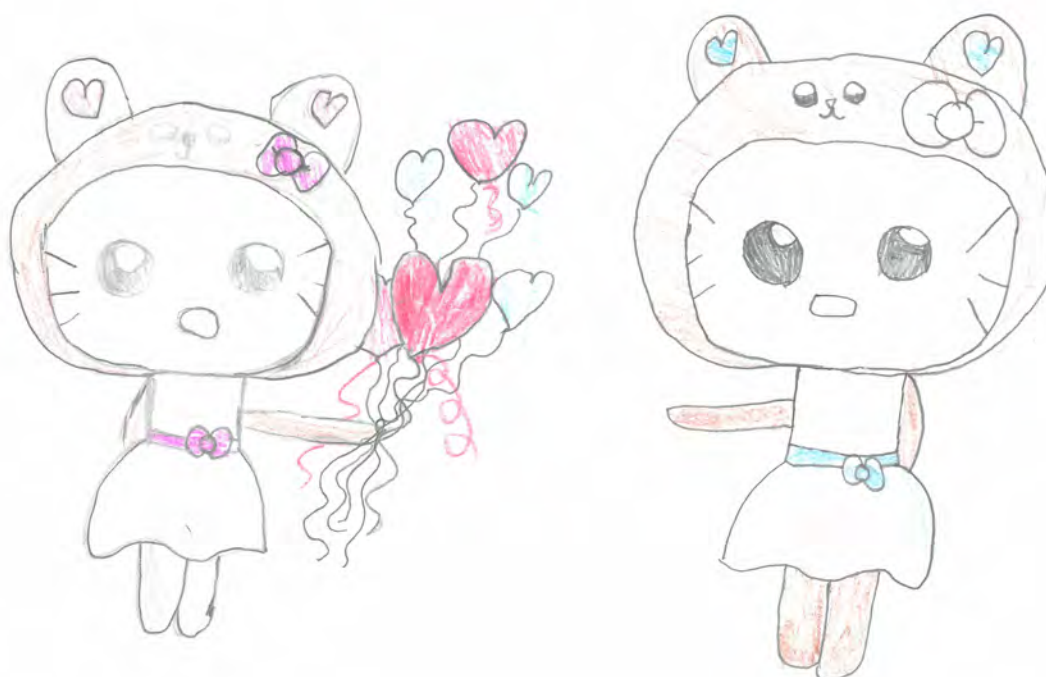
## When end of life care begins

While the introduction of end-of-life care can occur gradually or seemingly quickly, it begins when treatments or procedures are no longer effective at reducing the burden of their life-limiting condition. The family of the child or young person with a life-limiting condition will have been informed throughout this process and be aware of the transition from active treatment to quality of life and pain management. The family may not feel comfortable or ready to discuss that end-of-life care has begun; acknowledging this can be a very painful topic.

It can be surprising to see the differences of care in this stage of palliative care. You may see changes in food habits, movement, toileting, breathing and skin appearance. It is important to remember that end of life care does not play out like an episode of a TV

show or a movie. The experience is vastly different for each child and family. The palliative care team will be present through the end-of-life journey and will also be a support network for the family. Some families choose to receive end of life care in a hospital or hospice, wishing to have the support of the health care team as they navigate this painful journey. Other families may wish for their child to be in their own home and in the environment where they feel safest.

For everyone involved in the child's life, end of life care can be a moment of acceptance and peace, knowing that suffering will ease, and everything that can be done, has been done. It can also be a moment of anguish, pain, and denial, remembering that at the end of this journey a child will die. These feelings and moments can be interchangeable, fleeting or remain consistent.



## HELPFUL HINTS

When end of life care begins, remember that this journey can be difficult. It is important to focus not on the death of the child, but on easing the journey of end-of-life care for all involved.

Being there for the family is the best way to support them, in whatever capacity they need. Some families will only wish for a few people to surround them. Other families may want to throw a party for the child so that many of their friends and family can be there to provide support. And, of course, there are many options in between.

There is no right or wrong way to complete end-of-life care and it is important to focus on the quality of a child's life rather than what alternative active treatment can be done or should be done.

## Tips section

- Take time for yourself – this can be a distressing situation for everyone involved and recognising where your limits are is important.
- Think about practical help and tasks you can do for the family to assist in this difficult time (mowing the lawn, dropping off meals, laundry, grocery shopping, taking care of siblings, walking the dog). Toward the back of this toolkit are Task Vouchers which can be dropped off to families facing end of life care to demonstrate that you are available to support them when they need it the most.
- Don't expect anything in return – be present and know that the family may not have the energy to respond to all messages and phone calls. Being there in the moment as much as you can is what the family will remember.





# FOURTH STAGE: SO MUCH PAIN

## After death care for the family

Palliative care does not end once a child passes away. Afterwards, there are still grieving family members and friends, who still need support and care. It is important to continue to honour the child's life and allow everyone to mourn in whatever way they choose.

The family will have their own way of grieving, which can include spiritual or cultural norms that they will lean on during this difficult process. It is important to think of the child's siblings at this point; they may

want privacy or need a safe space to ask questions. The palliative care team will keep in contact with the family following the death of a child. There will often be a need to lean on others to get through this difficult time. This could include help with household chores, running errands or helping plan a funeral.

Being a supportive person for the family, and a safe space for people to lean into, is especially important in after death care. Not all people feel able to be this person and recognising the best ways that you can provide help and support is extremely important.



## HELPFUL HINTS

Throughout this time, we recognise that it is not just the family who are grieving. Anyone who knew the child will feel a sense of loss and may need to reach out to others for support as they navigate this period. Taking time for yourself to grieve on your own may be valuable, especially if you have spent a lot of time being a support person for the family and child.

### Tips section

- Be honest with yourself and those around you. Don't tell yourself and others that you are okay if you are not.
- Don't avoid topics about the child. The child will always be a part of the family unit, and it is important to know that memories are present for everyone.
- Be sincere with your actions – remember birthdays and reach out on those days to check in with the family.
- Allow the family to have a safe space to come to where they can share how they feel.
- Remember that it's ok to feel vastly different throughout the day – some moments you may feel happy or laugh thinking back to a particularly happy moment and at other times you may feel a deep sense of loss and grief.
- Remember it's ok to not know what to say or do – many people do not have the ability to put into words how they feel during the grieving process. You are not expected to have the answers regarding this deep loss, however, being present is something that is always remembered.
- You do not have to start a conversation about a loved one who has died, but don't ignore people bringing them up, and don't over inflate the topic. It is not a one size fits all area.
- There are specialist bereavement counsellors that can help the family (and you) navigate through immense grief.

A reflective journal has been provided at the end of this toolkit. It is important to discuss how you feel during a child's palliative care journey. The journal provides an opportunity for everyone to have a space to discuss how the journey has impacted them and what support they need.



# MEMORY MAKING:

Throughout the palliative care journey, it is important to recognise the value of memory making. Children still want to be children, regardless of their life limiting condition, and creating meaningful memories allows them and their families to come together in a positive way.

Some memory making activities can be grand gestures, while others can be small activities that don't cost much or take much energy for the children. Involving children and their parents to determine what they would value as a memory making activity is key.

Work with children to create a wish list of things they would like to do. Talking about, and doing, activities, adventures, and experiences they've identified as wanting to accomplish is a wonderful way to create memories with children and their families. Ideas are provided here to help you start a conversation about what would bring them happiness and enjoyment.

Some children may be too sick to travel or may be too young to understand the activity. These activities are intended for the children, but remember they are also for their families and potentially you. They should suit the needs and wishes of the family and the unwell child. If you are unsure about which memory making activities are suitable, always discuss your ideas with the family.

Sometimes just talking about them will bring joy.

## MEMORY MAKING IDEAS

- ☐ Sensory play
- ☐ Music and dancing
- ☐ Milestone or activities such as driving a car, going to a formal or school dance
- ☐ Religious or cultural rites of passage i.e. First Holy Communion or Bah Mitzvah, Diwali or Lunar New Year
- ☐ Going to a concert, museum, art class, cooking class
- ☐ Go to a class for a hobby they're interested in
- ☐ Bowling
- ☐ Arcades
- ☐ Camping – both indoors and outdoors
- ☐ Horse riding
- ☐ Learning how to do their makeup
- ☐ Car shows
- ☐ Lego
- ☐ Making candles
- ☐ Bookmark making
- ☐ Spa day
- ☐ Photoshoot
- ☐ Trying foods, they haven't had before
- ☐ Going to the zoo & feeding and patting animals
- ☐ Birthday party with fun games to play
- ☐ Gardening (at care facility if needed)
- ☐ Going on a boat
- ☐ Bike riding
- ☐ Going on a plane
- ☐ Board games
- ☐ Building/designing a project such as a piece of furniture or cubby house

# RESOURCES

## RESOURCES FOR YOU AND OTHERS

There are a variety of wonderful resources available to the community to help provide support during this difficult time. It is important to recognise your strengths in being a part of the palliative care journey, but also to seek help and support when it is needed. Some families may also not be aware of the resources that are available to them, so being aware of what is out there can be a great way to provide support.

### Books - Children's

- The Goodbye Book by Todd Parr
- The Invisible String by Patrice Karst
- Ida, Always by Caron Levis
- The Memory Tree by Brita Teckentrup
- Tough Boris by Mem Fox
- Duck, Death and the Tulip by Wolf Erlbuck
- When Tough Stuff Happens by Tricia Irving
- Modern Loss by Rebecca Soffer and Gabrielle Birkner

### Self-directed journalling

- The Sadness Book by Elias Baar
- Burn after writing by Sharon Jones

### Books - Adults

- It's okay that you're not okay by Megan Devine
- Bearing the Unbearable by Joanne Cacciatore
- The Other Side of Sadness by George Bonanno



My family and my dog make me happy.





# RESOURCES

## Australian Capital Territory based resources:

Palliative Care ACT  
[pallcareact.org.au](http://pallcareact.org.au)



Leo's Place by Palliative Care ACT – Leo's place offers overnight and day respite to people with life-limiting illnesses and their families. They also provide carer support and activities the whole family can attend.  
[leosplace.org.au](http://leosplace.org.au)



Grief Counselling:

The Grief Centre  
[canberragriefcentre.com.au](http://canberragriefcentre.com.au)



Compassionate Friends ACT  
[compassionatefriendsact.org](http://compassionatefriendsact.org)



## Australia wide resources

Lifeline – crisis support hotline  
[lifeline.org.au](http://lifeline.org.au)



Canteen – youth cancer charity  
[canteen.org.au](http://canteen.org.au)



Black Dog Institute – mental health support and research  
[blackdoginstitute.org.au](http://blackdoginstitute.org.au)



Rednose – grief and loss services and charity  
[rednose.org.au/section/about-us](http://rednose.org.au/section/about-us)



A Family Companion by Paediatric Palliative Care  
[paediatricpalliativecare.org.au/resource/a-family-companion](http://paediatricpalliativecare.org.au/resource/a-family-companion)



Kite Crew App by Red Kite: This is an app available on Apple or Google store, where you can invite people into a group, set tasks that need to be done, provide updates and review resources. This is a great App for when families need help with practical tasks or needs to let a lot of people know about the progress of a child's condition.  
[redkite.org.au/how-we-help/kitecrew/](http://redkite.org.au/how-we-help/kitecrew/)



Information on paediatric palliative care  
[paediatricpalliativecare.org.au/carer](http://paediatricpalliativecare.org.au/carer)



Starlight moments by Starlight Children's Foundation. Starlight Moments creates experiences of fun, joy and happiness for families with a palliative child, creating moments that matter to each individual family. The organisation also supports families for 12 months after the passing of a child.  
[starlight.org.au/about-us/what-we-do/starlight-moments](http://starlight.org.au/about-us/what-we-do/starlight-moments)



# TASK VOUCHERS:

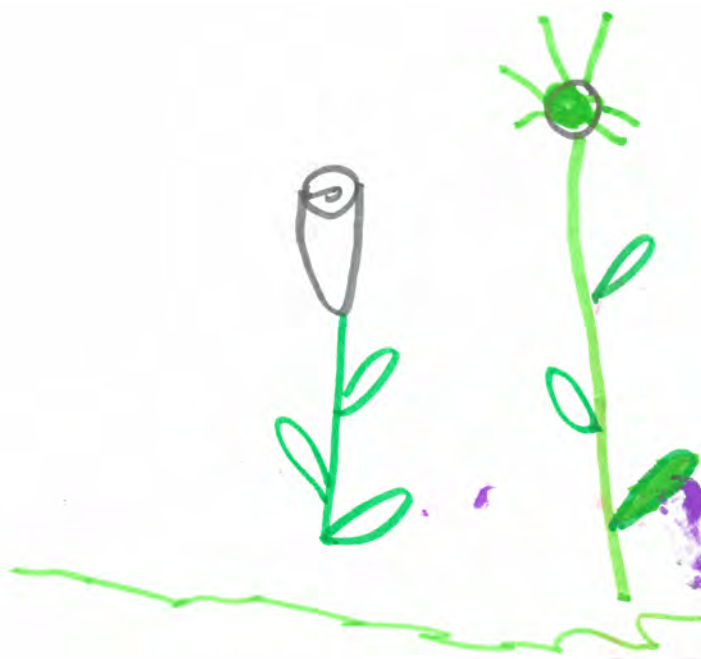
## HOW YOU CAN HELP

One of the best ways to support families and children with life-limiting conditions is to offer support and care in a way that suits you and your ability to help. It is important to only offer a level of support and assistance that is not detrimental to you or your own quality of life.

Sometimes families require support and do not know how to ask for it. At other times, members of the community want to offer support and do not know the best way to do this. We have created some task vouchers that may help you to offer a level of support that suits the needs of a family. These task vouchers can be dropped off with a family, who can then see that you are available to help but recognise that it needs to be at a time convenient for them.

There are so many ways to support a family and child undergoing palliative care including:

- Offering to take children and families out for lunch or coffee
- Creating photo albums and photo collages
- Organising charity fundraisers to support the family
- Helping raise awareness of the life-limiting conditions





This is a voucher for

## MOWING THE LAWN

Please contact me at any time to use this voucher, contact details are on the back

This is a voucher for

## WASHING/LAUNDRY

Please contact me at any time to use this voucher, contact details are on the back

This is a voucher for

## RUNNING ERRANDS

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## RUNNING ERRANDS

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## GROCERY SHOPPING

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## GROCERY SHOPPING

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This is a voucher for

## TAKING KIDS TO SCHOOL

Please contact me at any time to use this voucher, contact details are on the back

This is a voucher for

## TAKING CARE OF YOUR PETS

Please contact me at any time to use this voucher, contact details are on the back

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## PRE-PREPARED DINNERS

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## PRE-PREPARED DINNERS

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## BABYSITTING

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## BABYSITTING

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# REFLECTIVE JOURNAL:

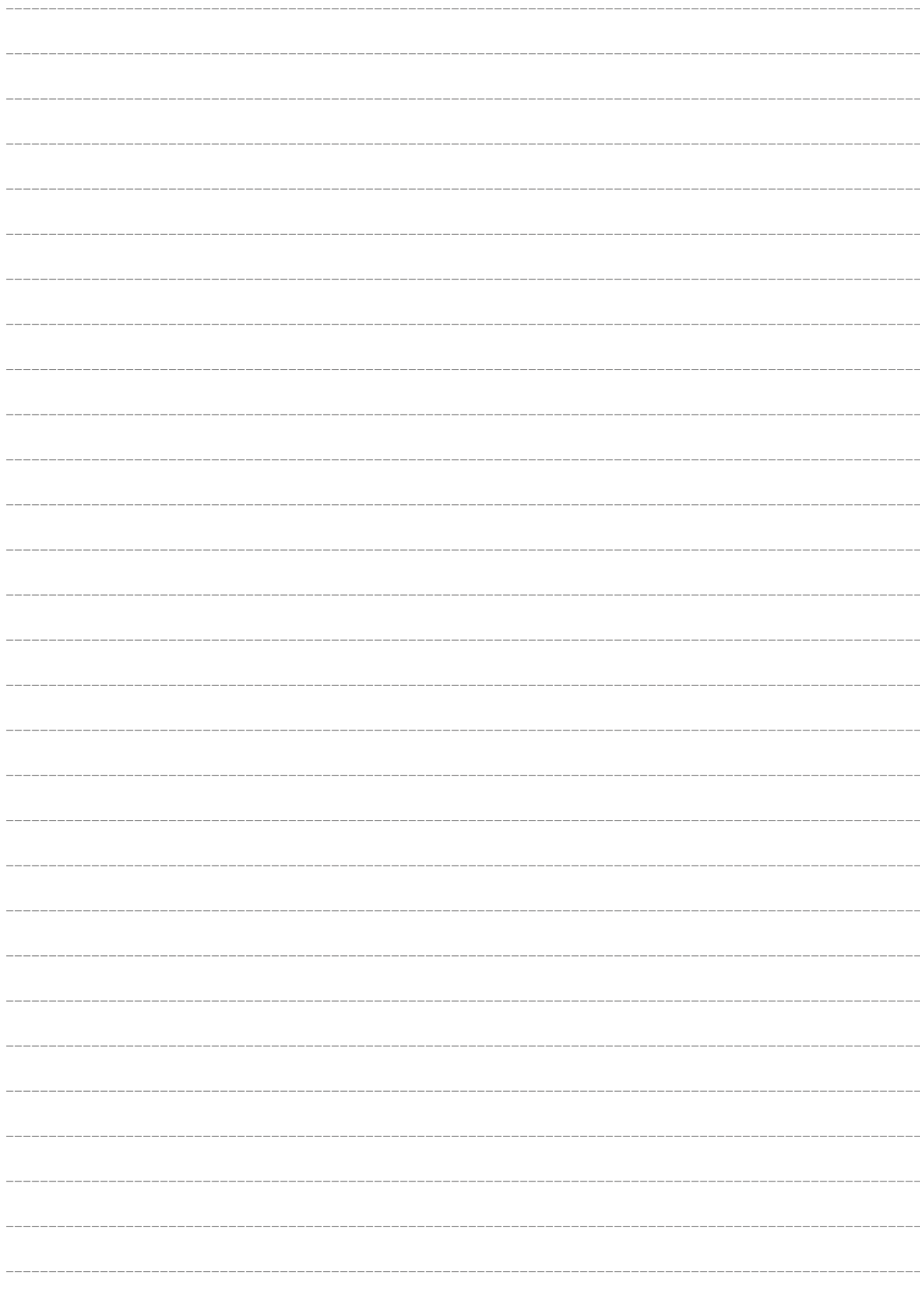
This journal space offers prompts to help you discuss how you are feeling about a palliative care journey and the grieving process. As a supportive member to a child with a life-limiting condition and their family, you are a part of their journey, and your feelings and emotions are valid.

Some ideas of questions to make a start in your reflective journalling include:

- What has been happening recently (What is the story)
- How do I feel about this palliative care journey?
- What feelings am I most uncomfortable with right now?
- Who can I count on to help me through my feelings and grief?
- Have I allowed myself to enjoy life now and then?
- What gives me comfort right now?
- What has previously helped me get through other tough times in my life?
- What moments have I been taking for myself?



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## ACKNOWLEDGEMENT

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Alwina - 11, Erik- 8, Frankie - 8, Isaac - 2 ,  
Isla - 5, Klara - 7, Matilda - 3, Mei - 5, Misha - 9

## FOR MORE INFORMATION



VISIT  
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