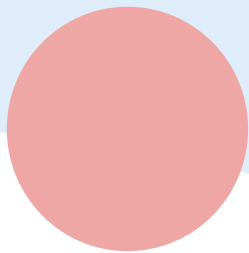




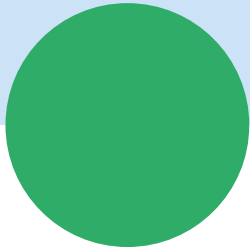
**Paediatric  
Palliative care**  
NATIONAL ACTION PLAN PROJECT

# Support to assist you on your Palliative Care Journey



November 2023

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This resource is dedicated to providing compassionate support and comprehensive information for those embarking on the challenging path of palliative care. Understanding that each journey is unique, we strive to offer a guide that respects your individual experiences and needs.

In this resource, you will find a wealth of resources tailored to assist patients, families, and caregivers navigating the complexities of palliative care. Our aim is to empower you with knowledge, support, and practical advice, ensuring that you feel heard, understood, and cared for every step of the way.

Remember, you are not alone on this journey. This resource is a companion, designed to walk alongside you, offering support and direction during this significant phase of life.

### Acknowledgement

Prepared with thanks by Heather Renton and Kris Pierce

### Disclaimer

The information in this Paediatric Palliative Care fact sheet is intended for the purpose of disseminating information regarding a range of Government and other supports that may be available to children living with disability, to carers, and following the death of a child. The information is correct to the best of Paediatric Palliative Care Australia's knowledge at the time of publication. Commonwealth, state and territory government financial and other supports, and initiatives offered by businesses, not-for-profit entities and charities are subject to change, including without notice.

Paediatric Palliative Care Australia does not guarantee and accepts no legal liability whatsoever arising from or connected to the accuracy, reliability, currency or completeness of this Paediatric Palliative Care fact sheet. Nothing contained in this fact sheet is intended to be used as legal or medical advice and is not a substitute for professional advice.

We encourage you to exercise your own skill and care, and undertake your own planning and research, regarding the supports that may be available to you or your child.

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# Carers

As a caregiver, you may be eligible for various payments based on your situation and the needs of the person you care for.



## **Carer Payment**

This is suitable for those providing continuous care to someone with a disability and/or medical condition. Continuous care involves a significant daily time commitment, similar to a full-time job. If this level of care prevents you from working full-time, you may qualify for this payment, noting this payment is means tested.



## **Carers Allowance**

This supplementary payment is for caregivers of individuals requiring daily support. This payment is also means tested. It's applicable if the person you're caring for has a terminal medical condition or needs regular daily assistance for at least 12 months.

You can receive both Carer Payment and Carer Allowance simultaneously, depending on your specific circumstances.

Additionally, if you're working or studying full time, you can claim Carer Allowance along with other **income support payments** such as Disability Support Pension, Youth Allowance for students and Australian Apprentices, or Parenting Payment.



## **Annual and one-off payments**

If you're receiving Carer Payment, Carer Allowance, or both, you might also qualify for other types of financial support:

### **1. Carer Supplement**

This is an annual payment designed to help with the expenses of caring for someone with a disability or medical condition. You'll receive this supplement automatically if you're getting an eligible carer payment over any period that includes 1 July.

For those caring for children, there are specific payments:

### **2. Child Disability Assistance Payment**

This is another annual payment for those who receive Carer Allowance. You automatically get this payment if:

- You're getting Carer Allowance over any period including 1 July, and
- You're providing care for a child with a disability or severe medical condition.

### **3. Carer Adjustment Payment**

This is a one-time payment for carers of a child under 7 years old, who has been diagnosed with a severe medical condition or disability after a major incident. To receive this payment, you need to demonstrate a significant need for financial support.

You might also be eligible for a Health Care Card, which can help reduce healthcare costs.

More details are available at [Services Australia](https://www.servicesaustralia.gov.au).

## Supplementary Support for Carers

Carers make an important contribution to the lives of the people they care for and the communities in which they live. Each state offers different supports.



### **Carer Discount Cards**

#### **1. Companion Card (National)**

The National Companion Card brings together state and territory programs that enable eligible people with disability who require attendant care support to participate in attending venues and activities without incurring the cost of a second ticket for their companion.

States and territories are responsible for issuing Companion Cards and eligibility varies across states.

#### **2. Carer Business Discount Card QLD**

The Queensland Government's Carer Business Discount Card recognises and supports carers, including approved foster and kinship carers, by providing discounts on goods and services at participating businesses throughout Queensland.

This card is for people with significant and permanent disability who have a lifelong need for a high level of support to participate in community events and activities. The card allows a person's carer free entry into participating venues and events.

#### **3. Carer Card (Vic Only)**

The Victorian Carer Card recognises the significant contribution carers make to the lives of people they care for and the communities in which they live. It provides discounts and benefits to carers in acknowledgement of this contribution.

## Support Organisations for Carers

Your palliative care team, including your social worker (if you have one), is a valuable resource for accessing a wide array of services. The below overview is not a comprehensive list of all the available supports and services as these continue to expand and evolve over time. Your care team will have the the most current information and may be able to assist you with tailored supports to meet your needs.



### **Carers Australia**

Carers Australia is the national peak body representing Australia's unpaid carers, advocating on their behalf to influence policies and services at a national level.

Carers Australia advocates and lobbies on a wide range of issues that affect carers. We also manage the delivery of national programs, support and services for carers across Australia.

Carers Australia works in collaboration with carers, Carers Associations, government advocates, and peak bodies to develop policy, programs and events to improve the lives of Australia's 2.65 million carers.



### **Carer Gateway**

Carer Gateway is an Australian Government program providing free services and support for carers.

If you care for a family member or friend with disability, a medical condition, mental illness, or who is frail due to age, then Carer Gateway can help you.

The Australian Government works with a range of health and carer organisations across Australia, known as Carer Gateway service providers, to deliver services to carers no matter where they live in Australia.

Carer Gateway provides many services to support carers in their caring role, including:

- » in-person and online peer support groups
- » tailored support packages to help with accessing planned respite, transport services, and more.
- » in-person and phone counselling
- » in-person and online self-guided coaching
- » online skills courses to support your wellbeing and understanding of legal responsibilities relating to the caring role
- » access to emergency respite if you suddenly find you can't provide care, for example if you become ill or injured.

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# Children's Disability Support Organisations



### Kiind (WA)

Supports families raising children living with disability, developmental delay, autism, genetic, rare, undiagnosed and/or chronic conditions.



### Association for Children with a disability (VIC)

Helps families gain the knowledge, skills, and confidence to advocate for their children with disability. They provide support to families with children from birth to 18 and professionals working with them.

The services are free and include:

- » Information resources
- » Workshops and peer support
- » The ACD Support Line – a telephone advocacy service



### Kindred (NSW)

An independent, not-for-profit peer support organisation for families of children with disability, developmental delays and medical needs.

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# Playgroups



### MyTime

Mytime organises supported groups where parents and carers of children with disability or other additional needs can feel understood, share ideas, and access quality information and resources.



### PlayConnect

Play Connect is the national representative body for playgroup organisations. You can find a list of playgroups around Australia on their website.

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# Childrens Hospices



### Children's Hospice

While many families choose to remain at home, sometimes this can be difficult and additional medical support is necessary. It is important to remember that you can always go to the hospital or hospice if you change your mind.

There are currently four hospice centres in Australia.

- » [Very Special Kids](#) – Melbourne, VIC 03 9804 6222
- » [Bear Cottage](#) – Sydney, NSW 02 9976 8300
- » [Manly Adolescent and Young Adult Hospice](#) – Sydney, NSW 02 9926 5700
- » [Hummingbird House](#) – Brisbane, QLD 07 3621 4364

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# Podcasts



### Life, Love and Loss

Podcast for families caring for a child who is dying.

This podcast series focuses on the experience of parents of children who have died or are likely to have a short life. Despite advances in health care, children and young people still sadly die from a range of life limiting conditions. The parents in this series have been supported by palliative care teams to face multiple challenges in caring for their children. These parents bravely share the love and beauty of their children and the joy and sadness of their individual experiences. They hope their voices can support, inform, and better prepare other families who may need to face similar challenges.



### Too Peas in a Pod

A Podcast by Mandy Hose and Kate Jones who chat to each other and friends about parenting multiples with disabilities and additional needs.

## Travel Information



### **Hidden Disability Sunflower**

The Hidden Disability Sunflower scheme offers a number of different accessories; badges, lanyards and wristbands that people can voluntarily wear to raise awareness of the fact they have a disability or condition that may or may not be immediately apparent and that they may need a helping hand, understanding, or more time in shops, at work, on transport, or in public spaces.



### **Australian Disability Parking Scheme**

The Australian Disability Parking Scheme (ADPS) includes an Australian Disability Parking Permit, which is recognised nationally. It also establishes nationally consistent eligibility criteria and national minimum parking concessions to help reduce the barriers for permit holders when travelling interstate. State and Territory Governments are responsible for the management of the ADPS.

Enquires about permit applications, cost, eligibility, and use should be directed to the relevant State or Territory authority.



### **Interstate Travel – Disability concessions and medical support programs**

#### **1. Qantas Carer Concession Card**

This concession card needs to be purchased from [People with Disability Australia](#) for \$49.50 (inclusive of GST). The card provides discount travel on domestic Qantas flights for eligible people. It is issued to people with significant support requirements who are unable to travel on an aircraft without the full-time assistance.

#### **2. Qantas Disability Access Facilitation**

Plan provides a mechanism to ensure your travel experience that is comfortable and smooth as possible whilst accommodating your disability.

#### **3. Jetstar Disability Access Facilitation Plan**

Sets out the process and assistance Jetstar offer customers with disabilities.

#### **4. Oxygen required during flights**

Many airlines don't allow personal portable oxygen cylinders on board. Instead, you might need to hire an airline-approved oxygen cylinder or use the airline's in-flight oxygen service. Remember, if you use the airline's oxygen, you usually can't take it off the plane. So, if you have a stop-over, you'll need to arrange a separate oxygen supply for the time you're on the ground between flights.

Some portable oxygen concentrators are suitable for use on planes and during stopovers. However, it's important to check if the airline you're flying with allows these devices. You might also need to reserve a seat near a power source to keep the concentrator's batteries charged, especially on long flights where the device needs to work for many hours.



## Payments for Your Child



### **Disability Support Pension for people over the age of 16**

If your child is over 16 years old and has a physical, intellectual, or psychiatric condition that's expected to last more than 2 years, and limits their capacity to work, they might be eligible for financial assistance through the Disability Support Pension. You can work up to 15 hours without compromising some of your pension.



### **Pensioner Education Supplement**

This is a regular payment to help with your study costs if you get a disability pension. You must be studying an approved course and be studying full time, in some circumstances part time will be considered.

More details are available at [Services Australia](#).

# Death of a Loved One



## **Support Services**

It's normal to feel hesitant about engaging in social activities during grief. There are support services like counsellors to help you through these times. Talk to your doctor or local community health centre about your situation for information and referrals to support and counselling services.



## **Counselling through Community Organisations**

Community Health Centres in Victoria offer state-funded primary healthcare, focusing on people with or at risk of poorer health. The National Association for Loss and Grief acts as a support network for those experiencing loss and grief, offering services to individuals, families, and communities.



## **Online Resources and Support Organisations**

- » **Australian Centre for Grief and Bereavement**: Offers online resources for grief.
- » **Bears of Hope**: Provides support for families after the loss of a baby.
- » **Beyond Blue**: Offers confidential counselling 24/7.
- » **Griefline**: Provides telephone and online counselling services.
- » **Headspace**: National youth mental health foundation assisting young people through tough times.
- » **Head to Health**: Digital gateway for online and phone mental health services.
- » **Lifeline**: Offers 24-hour crisis support and suicide prevention services, with accessible counsellors.
- » **Red Nose Grief and Loss**: Offers online and telephone services for parents and families after the death of a child.
- » **The Compassionate Friends Australia**: Provides support to bereaved parents, siblings, and grandparents.



## **Other Useful Resources**

- » **Organ donation factsheet**
- » **Tissue donation factsheet**
- » **Brain death factsheet**
- » **Bereavement support resources**



## **Legal requirements**

There are several forms you'll need to complete before the funeral. These forms, along with advice about funeral arrangements and the accompanying legal procedures, can be obtained from a funeral director or cemetery authority.



## **The Death Certificate**

The Extract of Death may not be automatically sent to you if your child was under 16 years of age. You can request an Extract be sent to you from the Registrar of Births, Deaths and Marriages. It is free. If your child was 16 years or over, an Extract of Death is automatically sent to the person who completed the legal forms. A full death certificate can be obtained for a fee.

# Financial Supports following the Loss of a Child

## > Family Tax Benefit (FTB)

After the loss of an eligible child, you can still receive the Family Tax Benefit. This can be as a fortnightly payment for up to 14 weeks, or as a one-time lump sum.

If you haven't yet claimed FTB for your child, you can either apply for a bereavement payment now or claim FTB as a lump sum at the end of the financial year. The amount and duration of the payment depend on your family's income and the age of each child in your family.

If your child passed away before their first birthday and you received a lower Newborn Supplement, you may also receive a top-up with your FTB bereavement payment.

## > Parenting Payment

Single parents whose only qualifying child has passed away can continue receiving Parenting Payment for up to 14 weeks after the child's death. After this 14-week bereavement period, if ongoing income support is needed, you can apply for another payment using the online Payment and Service finder.

## > JobSeeker Payment or Youth Allowance

If you're a single principal carer and your only qualifying child has passed away, you'll continue receiving the higher rate of payment and concessions for 14 weeks after your child's passes away. This applies to those receiving either JobSeeker Payment or Youth Allowance. Your mutual obligation requirements will also be reduced for up to 14 weeks after your child's passes away.

## > Carer Allowance

If you're receiving Carer Allowance for a child eligible for FTB who passes away, you can get a Carer Allowance bereavement payment. This will be paid as a lump sum covering up to 14 weeks from the date of the child's passes away.

## > Carer Payment

If you're receiving Carer Payment for a child who has passed away, you may continue to get this payment for up to 14 weeks after the child's death. This period is to allow time to apply for another income support payment, if needed. A lump sum bereavement payment is also provided, and you can use your concession card for up to 14 weeks after your child passes away.

## > Medicare, Concession, and Health Care Cards

Your Medicare card, concession card, or Health Care Card will not be automatically reissued if your child passes away. If you wish to have a new card, you can contact Medicare general enquiries to request one. Otherwise, the details on your current card will remain the same until it expires.



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