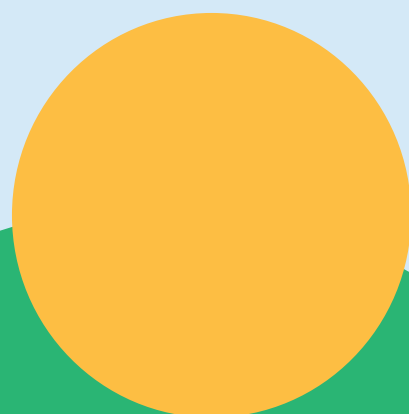
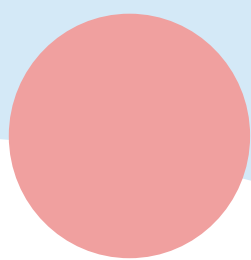




**Paediatric
Palliative care**
NATIONAL ACTION PLAN PROJECT

Paediatric Palliative Care and the National Disability Insurance Scheme Resources



November 2023

This project was funded by the Australian Government.

This document is designed to give readers a brief overview of the National Disability Insurance Scheme (NDIS) from a carer's perspective of looking after a child who is a NDIS participant receiving palliative care.

This resource is written from the viewpoint of a parent being the child's NDIS plan and correspondence nominee.

We encourage you to do your own research and refer back to the [NDIS website](#) for the most current information, videos and checklists.

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 to potential and current NDIS participants and their representatives. The information is correct to the best of Paediatric Palliative Care Australia's knowledge at the time of publication. Legislative requirements, policies, guidelines, processes and other information related to the NDIS 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, when engaging with the NDIS.

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What is the National Disability Insurance Scheme (NDIS)?

The National Disability Insurance Scheme (NDIS) is a scheme that supports people who are born with or acquire a permanent (lifelong) or significant disability that impacts a participant's everyday life, preventing them from doing everyday tasks and activities.

The scheme is administrated by the National Disability Insurance Agency (NDIA). The NDIA is the organisation that is responsible for approving NDIS participants and their NDIS plans.

The NDIS is governed by the [National Disability Insurance Scheme Act 2013](#) and Section 34 of the Act means the scheme can fund “reasonable and necessary” supports and services so a participant can achieve their NDIS goals. There are six criteria that constitute ‘reasonable and necessary’ in the Act. In plain English, ‘reasonable and necessary’ supports:

- » Assist a participant to work towards achieving their goals, objectives, and aspirations.
- » Help participants engage in social and economic activities.
- » Demonstrate good value for money relative to alternative supports.
- » Need to be regarded as current good practice and be effective and beneficial to participants.
- » Take into consideration what is reasonable to expect from a participant's family members, carers and other informal supports to do in their role supporting participants.
- » Are most appropriately funded by the NDIS instead of another service, e.g., the Federal Department of Education or the Federal Department of Health and Aged Care, or another state or local government service.



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How can you access the NDIS?

To access the NDIS, participants need to meet the NDIS access criteria. If your child's condition is deemed palliative, it does not mean they will automatically receive entry to the NDIS. The NDIS supports people with disability; it is not a healthcare scheme.

The NDIS has access criteria in section 21 of the [National Disability Insurance Scheme Act 2013](#). For children to meet the NDIS access criteria, they need to:

- » Be an Australian resident, permanent visa holder, hold a special category visa, or satisfy other residential requirements prescribed by the NDIS rules.
- » The child has to have a permanent or significant disability that impacts the participant's functional capacity that impacts their daily life.
- » The disability must be either (or a combination of one or more impairments) intellectual, cognitive, neurological, sensory or physical impairments or one or more impairments attributable to a psychiatric condition.
- » Meet the early intervention requirements of development delay/concerns or disability.

Note: If your child does not meet the NDIS access requirements, they can still receive community supports and other government services through community partners and the NDIS, who can provide them with information about supports and services in their community and other government supports. This information can be provided by Early Childhood Partners and Local Area Coordinators (LACs).

To become a participant of the NDIS, an [access request form](#) needs to be submitted to the NDIA. You must complete the form and submit it with supporting evidence such as your child's disability, diagnosis (if known) and other reports such as a functional capacity report and allied health professional reports.

Sometimes your child's health team may be able to assist you with your NDIS access request form, including but not limited to providing supporting evidence to help your child receive the services and supports that can best assist them under the NDIS. You may wish to consider asking your child's palliative and clinical team for reports which can form part of the evidence that you supply to the NDIA. A health professional can also complete section 2, part E of the [access request form](#).

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Early Childhood Development Sector

The Early Childhood Development Sector assists all children to access supports, including those with developmental delays or disability.

Children with developmental delays or disability may require reasonable adjustments e.g., specific equipment, to help them be included and participate in their community or provide children with more support to engage in activities with their peers. Many children with palliative conditions will require additional supports to assist them with participating in their community.

Supports that build a child's capacity to become independent and potentially reduce how much support a child needs under the NDIS are more likely to be supported. To receive these supports, a child must also meet the NDIS funding criteria, including "reasonable and necessary" supports.

Early Childhood Approach

Early Childhood Partners deliver Early Connections which is part of the Early Childhood Approach, a national program that supports children under 6 years with developmental delay/concerns or disability or children younger than nine with a permanent/significant disability.

The NDIS funds this program, but your child does not have to be accepted into the NDIS to gain access to support. No diagnosis is needed to access this program.

There are many children with palliative conditions who benefit from this national program in their early years. Your child's GP, health nurse, health service or early childhood professional can help connect you to the right supports, if they can confirm there are developmental concerns.

Or you can contact the [NDIS](#) via their website, [email](#), phone: 1800 800 110 or webchat. You can find out more about [applying for the NDIS](#) on their website.

Early Connections are about ensuring you get the right services and supports to assist your child. It supports the child's development and the family's wellbeing, assisting you take part in your community.

Early Childhood Partners and Local Area Coordinator (LAC) partners are not located in all areas, including remote areas, so if this is the case the NDIA will work directly with these families.

Children older than 9 are supported by a NDIS LAC partner as NDIS participants if they meet the schemes access criteria. The NDIA tenders the contracts for Local Area Coordinators out, which means that different organisations operate as Local Area Coordinators in different areas around the country.



The Health System vs the NDIS

The health system is responsible for palliative care, including end-of-life care, as well as medical support that a child may need in and out of the hospital setting.



Health Liaison Officers and NDIS Participants in Hospital

Health Liaison Officers (HLOs) are employed by the NDIA and are located in public hospitals nationally. When a child who is a NDIS participant is admitted to hospital, healthcare staff notify the NDIA through their HLO, within four days of the hospital admission. This process ensures that the necessary supports are arranged for the child upon discharge.

HLOs play a key role in maintaining effective communication between the hospital and the NDIA. In situations where urgent support is needed for a child leaving the hospital, specialised planners work alongside HLOs to coordinate these efforts.



Navigating NDIS Access and Hospital Discharge

If a child is not yet a NDIS participant and is hospitalised, the hospital staff can suggest they meet the NDIS access criteria to become a participant. They can also assist with completing the NDIS access request form. However, the hospital team cannot submit the application on your behalf.

The hospital team can inform the NDIA's hospital discharge team about the child's situation. This team is also capable of conducting a home and living assessment if needed.

Should your child require additional support for discharge from the hospital, a planner from the NDIA's hospital discharge team will organise a planning meeting with your child's NDIS representative. In most cases, these plans are approved quickly, typically within 30 days.

The NDIA hospital discharge team can also conduct the planning meeting, write, and implement the plan with your child's NDIS representative.

Disability Related Health Supports

To be eligible for disability-related health supports, the support must directly relate to the child's functional impairment and disability. Disability-related health support may include a nurse or allied health professionals, a specific piece of equipment or respiratory support (note, each state, not the NDIS, funds oxygen).

The NDIS will fund supports directly related to your child's disability so they can participate in their community and daily life. The NDIS supports palliative children simultaneously as the health system that provides palliative care support. Paediatric palliative care is about children being supported to live their best life. It aims to improve the quality of life of children with life-limiting conditions and support their families. It helps their physical, medical and emotional health and wellbeing.

When your child is in palliative care, you may wish to consider supports to be included in your child's plan, such as:

- » Short-term accommodation (respite care)
- » Family counselling and emotional support

The NDIS has committed to maintaining NDIS supports concurrently with palliative care.



Navigating the NDIS

Once your child has been accepted on the NDIS, you will be contacted by an Early Childhood Partner, a Local Area Coordinator (LAC) or the NDIA (if your child's disability is very complex).

They will organise a planning meeting to talk about your child's goals and the supports required to work towards achieving their goals and aspirations and for them to participate in everyday life.

Preparing in advance for your child's NDIS planning meeting is a good idea. This may involve looking at the NDIS website and talking to other families with children on the NDIS. Speaking with parents whose children are also receiving palliative care can be helpful. Remember, most parents know their child best and understand their needs more than anyone. The preparation and the planning meeting can be stressful and overwhelming, but there are strategies you can take to help you prepare. These may include:

- » Thinking about what life is like for your child with a disability from their perspective, including activities and social things they may or may not like to engage in. (Participant's statement)
- » Considering what your caring role for your child entails, including coping supports you require to care for your child. (Carer's statement)
- » Collating a weekly schedule of a typical week for your child, including what education setting they attend, appointments they may have and activities your child engages in. (Weekly schedule)
- » Setting some goals for your child and considering the supports the NDIS may fund to help your child work towards their goals. (Goal setting)



Writing a Participant (About Me) Statement

As their plan representative, your child or you may like to write a participant statement about what life is like for them.

- » Include what life is like for your child in their daily life (be honest).
- » Who does your child live with?
- » Where do they go to childcare/kinder/school?
- » List what current formal and informal supports are in place to support them.
- » Mention what activities your child participates in and enjoys doing.
- » What activities and daily living tasks your child needs assistance with?
- » What social activities your child engages in, and what supports are required to be in place for them to access their community?



Writing a Carer Statement

Being a carer is not always easy, particularly when your child's health is deemed to be palliative. Be honest about what life is like for you and how your emotional and mental health is impacted directly by your caring role.

- » How does caring for your child impact you as a carer?
- » What do you find difficult, and what supports do you have in place to support you?
- » What support would you like to receive to make your caring role easier in supporting your child's everyday life?
- » How do you cope with being a carer and looking after your child?
- » What assistance do you have in place to support you?
- » How does being a carer impact your relationship with your family and others, including your capacity to work?



A Typical Week

Writing a weekly schedule of what a typical week looks like for your child will capture how your child participates in daily life. It demonstrates what your child's week looks like with regard to activities, appointments, and what happens inside the home. It may be helpful to include things like:

- » How frequently your child wakes during the night?
- » How long does it take carers to help your child with self-care activities such as hygiene and eating activities?
- » What social activities does your child do in the week?



NDIS Supports and Goals

The NDIS goals are targets participants want to work towards and achieve, such as building independence or participating in social activities and connecting with their community. Goals are not necessarily linked to your child's NDIS funding; however, disability-related supports are there to help your child work towards their goals. NDIS funding supports your child's goals, which are set by your child and/or their plan nominee.

Goals can be big or small, short-term or long term and as specific or as general as you like. They are individual for the participant. Small goals can be integrated into bigger goals. For example, a child may learn to clean their teeth as part of the bigger goal to become more independent. Goals assist in developing your child's NDIS plan. More information about [setting goals](#) can be found on the NDIS website.

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Ways to Manage Your Child's Plan

Plans can be managed in three different ways or a combination of the three ways. They can be managed by the NDIA, a Plan Manager or Self-Managed.



NDIA Managed

The NDIA manages your funding, so you are restricted to using services and supports provided by NDIS registered providers. You can find NDIS providers on the [NDIS providers portal](#).



Plan Managed

Your child receives funds in their NDIS plan, which funds a Plan Manager to pay your services and support providers' invoices on your behalf.



Self-Managed

The plan nominee manages their child's NDIS plan and is responsible for booking supports and services, paying their invoices, and claiming the funds back from the NDIS. When you claim funds back through the NDIS portal, they are usually paid into your child's nominated bank account within 24-48 hours. It is important to keep a record of your service and support provider's invoices, including any assistive technology items you have purchased, as the NDIS may audit you.

At your child's planning meeting, you will be asked how you would like to manage your child's NDIS plan. If you want to change how your child's plan is managed you can do so through requesting plan variation. You can nominate different parts of their plan to be managed differently. Please note a NDIS Registered Behaviour Support Practitioner can only develop a Behaviour Support Plan.

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Myplace Portal

The NDIS participants portal is called myplace. A new online portal and app are being rolled out over the next eighteen months called PACE. All new participants will have their plans created and available on PACE.

The current myplace online portal and PACE sit within the Australian Government's myGov website. This means you must create a [myGov account](#) to use the portal. On the portal, you can download or share a copy of your child's plan with service providers and other people. You can also receive messages from the NDIA. You can upload reports, assessments, service agreements and invoices if you choose.

Understanding NDIS Support Budgets for Your Child's Plan

The NDIS has three types of support budgets that are used to provide support in your child's NDIS plan. These are core, capital, and capacity building supports. These budgets are specifically for disability-related needs and not for general expenses.



Core Supports

Core Supports assist with everyday activities and community engagement. The funding is divided into four subcategories:

- » Assistance with daily life.
- » Transport.
- » Consumables.
- » Assistance with social, economic and community participation.

Funds can be interchanged between these categories unless marked as “stated”, which means they must be used for the specified category.



Capital Supports

Capital supports involve investments in equipment or home modifications. They include:

- » Assistive technology, categorised by cost:
 - Low cost: under \$1,500 per item, paid for from the participant's Core budget.
 - Mid cost: \$1,500 - \$15,000 per item, needing a therapist's letter of support.
 - High cost: over \$15,000 per item, requiring a quote for the support.
- » Home modifications and specialist disability accommodation.



Capacity Building Supports

Capacity building supports are designed to enhance a participant's functional capacity, skills and independence, working towards their goals. There are eight support categories, and you cannot be interchanged between them. The categories are:

- » Support coordination.
- » Improved living arrangements.
- » Increased social and community participation.
- » Finding and keeping a job.
- » Improved relationships.
- » Improved health and wellbeing.
- » Improved learning.
- » Improved daily living skills.

Understanding your Child's Plan

After your plan has been approved, your child's Early Childhood Partner, LAC, or Support Coordinator can help you understand and suggest ways you can utilise your child's plan.

They can recommend service providers for you and let you know different ways you can spend your support budget. They can assist you with putting service bookings and service agreements in place. They are a great first point of contact if you have any concerns.

NDIS Price Guide

The NDIS pricing guide may change more than once yearly at the NDIA's discretion. You can download the latest pricing guide from the [NDIS website](#).

The NDIS pricing guide sets the maximum rate that NDIS providers can charge. If you self-manage or plan manage your child's plan, you are not bound by the NDIS pricing guide rates, and some providers may charge above the NDIS set rates.

Any unspent funding in your child's plan that has not been spent when the new pricing guide comes into effect will automatically be increased to reflect the new pricing of the support.

Reviews

There are specific NDIS decisions that can be reviewed. These include:

- » Eligibility.
- » Funded supports.
- » Not doing a plan reassessments or plan variation.
- » How your funding is managed.
- » The plan length.

NDIS Plans can be Changed

If you're not satisfied with your child's NDIS plan or if there are changes in your circumstances, there are several ways to request a new plan.

Particularly for children receiving palliative care, the need for plan changes may arise more urgently. Your Early Childhood Partner, LAC or a NDIA representative can guide you on how to request modifications to your child's plan. They can also connect you with advocates who are specifically funded to assist you with the appeal process. During the review period, you can continue utilising the services and supports as outlined in your current plan.

Your child's NDIS plan could change if:

- » Their circumstances change.
- » You request an internal review of a decision.
- » You appeal the NDIS decision.
- » Your current plan expires.
- » You appeal with the Administrative Appeals Tribunal.



Change of Circumstances

If your circumstances change significantly, and your child requires more or less support, you can request a plan reassessment by lodging a change of circumstances form or calling the NDIA 1800 800 110. You can learn more about a [change in circumstance](#) on the NDIS website.



Plan Variation

Is a minor change to your child's current plan and only affects the part of the plan requiring the change. Examples of this might include a revised goal, a change in contact details or providing additional short-term funding if your circumstances change unexpectedly. You can request a plan variation as needed, and if the requested variants are approved, a new plan will be generated with a new start and reassessment date. Your new plan should be available within 7 days of the varied plan being approved.

A plan variation can be made in an emergency situation where your child's physical condition urgently requires more significant support, you can request a plan variation from the NDIA. Although the NDIA typically responds within 21 days, this response time may not be fast enough for children receiving palliative care who need more immediate and substantial support.

The NDIA will respond to a plan variant by:

- » Changing or not changing your child's plan as requested.
- » Requesting more time to review the request.



Plan Reassessment

Plan reassessments can be made face-to-face, over the phone or virtually. You can bring a support person, therapist, advocate, friend, family member or support coordinator to the meeting. You can request a plan reassessment at any time; however, the NDIA may take up to 21 days to respond to your request and may choose:

- » To vary your plan.
- » Provide you with a new plan.
- » Not to reassess your plan.

A plan reassessment involves your existing plan being reviewed and being superseded by a new plan. Sometimes, the plans will remain the same, and a new review date will be set if you are happy that the existing plan is fit for purpose. A participant or the NDIA can initiate plan reassessments.

Plan reassessments are required when there are significant changes required, as your plan no longer meets your child's needs or is no longer fit for purpose if their goals or functional capacity changes significantly or if your plan is due to expire soon and you require a new plan to meet your child's needs. Plan reassessments are required before your child's plan expires, usually around 3 months before. The NDIA will contact you about a plan reassessment. Most plans would be reassessed at least every three years to ensure they meet your child's needs. If nothing much has changed, you may receive a similar plan to your current one that includes the same supports and a similar budget.

Plan reassessments are made by having another planning meeting with your child's Early Childhood Partner, LAC or NDIA planner, who will generate a new plan for the NDIA to approve. They will ask you what is working well and not so well in your child's current plan, about their goals, if there are any changes you would like to make to their next plan or any anticipated changes to your circumstances, e.g., transitioning to a new phase of life. They may also question why you have not spent the allocated budget in your child's existing plan if this is the case.

It is a good idea to follow the process of preparing for your child's first plan, e.g., write an About Me and Carers Statement, provide a weekly schedule, think about your child's goals and collate current reports and assessments from clinicians and allied health professionals so you can build the evidence to support what services and supports you would like to receive in your child's next plan. It may be helpful to think about what a child without disability is doing in their life compared to your child, e.g., what community activities they are engaging in.

After the planning meeting, your new draft plan will be reviewed by the NDIA (this may take a couple of weeks). Once your new plan is approved, you can no longer use your old one, and new funding budgets and supports will be allocated to your new plan.



Internal Review

If you are not happy with the NDIA's decision in relation to your child's plan, you can appeal. The NDIA can explain the reasonings of their decision. If you are unhappy with their explanation, you can request an internal review. Internal reviews are usually completed within 60 days of the request for one. An urgent internal review can be requested if the situation is more urgent, e.g., a risk is involved.

In an internal review, staff who were not associated with the original plan or decisions will reevaluate the plan to see if they agree with it. If you are unhappy with the outcome of the internal review, you can request a review of the decision by appealing (external review) to the [Administrative Appeals Tribunal](#).

What Do I Do if My Child Passes Away

The NDIS has a Bereavement empathetic support team who can support families whose child has passed away. They can support you with NDIS related matters and get your concerns resolved quickly, including stopping NDIS funded supports.

Any person can notify the NDIA on your behalf that your child has passed away. The NDIA will ask for your child's name, contact details, date of birth and NDIS number (if you can provide it). Or you can complete a - [Notify the NDIA when a participant dies form](#) on the NDIS website.

Complaints

The NDIS is committed to improving its standards; if you are unsatisfied, you are welcome to complain. You can raise your concerns by email, telephone or by completing an online form. More information about [making a complaint](#) can be found on the NDIS website.

The NDIA will acknowledge your complaint within 1 day, contact you within 2 days, and resolve it within 21 days. If you are unsatisfied with the outcome, you can complain to the [Commonwealth Ombudsman](#).

You can provide the NDIA with feedback or make a complaint to the NDIS Quality and Safeguards Commission (NDIS Commission). The NDIS Commission aims to improve the safety and quality of NDIS services and support. They investigate NDIS service providers to ensure they comply with their duties and obligations and that the NDIS supports they provide are delivered safely, ethically, and appropriately. More information about the [NDIS Commission](#) can be found on the NDIS website.

Interpreters

The NDIS is committed to supporting people from Culturally and Linguistic Diverse Backgrounds and Aboriginal and Torres Strait Islander participants. LACs can arrange interpreters in a participant's preferred spoken language at no cost to the participant.



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