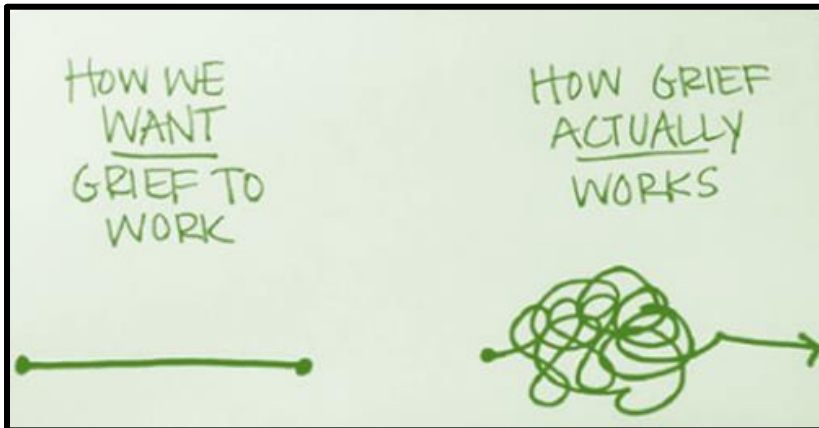


My child has been diagnosed with a disability – what happens next?

When your child has been diagnosed with a disability, mental health or other condition, it can stir up a lot of different feelings and trigger a process similar to grieving, as you cycle (often randomly and repeatedly) through feelings of denial, guilt, fear, sadness, depression, disorganisation, lethargy, anger, guilt and acceptance.



Often parents can process different emotions at different times, and this can create disagreements, stress and conflict in your relationships. You may also be uncertain as to whether to tell your child about the diagnosis or not. If any of this sounds applicable to you, consider accessing some counselling – either for yourself or as a couple, as you work through the diagnosis and what this means moving forward.

For older children who are aware they have been diagnosed, you may want to explore some specialised counselling or support to help them understand and process what this means for them.

Free counselling for carers is available through:

- Carers WA on 1800 007 332 or
- Carer Gateway Counselling Service on 1800 422 737

What do I need to do?

- 1) **Let your school know about the diagnosis** and give them a copy of the report, as they may be able to access extra resources to help them better support your child's learning. It can be helpful to book an appointment with them to discuss what the diagnosis means to you as a family, and what it means to them in the context of your child's learning.
- 2) **Explore whether you are able to apply to NDIS.** The National Disability Insurance Scheme (NDIS) provides funding for eligible individuals so they can access a range of supportive services to help with their disability needs. Their application form is available online at www.ndis.gov.au. If you require help with completing an application, or want more information, you can ask an LAC – Local Area Coordinator to help you. To access an LAC, call 1800 800 110 and ask to be linked with your Local Area Coordinator.
- 3) **Explore whether you or your child are eligible for any financial supports.** Centrelink offers a range of financial supports for families impacted by disability – such as Carer Allowance or Carer Payment depending on the severity of the disability/condition or Disability Support Pension for your child if they are 16 or older.

How do I apply for the NDIS?

- 1) Download the application form from the NDIS website – simply google NDIS Access Request Form to find it. Sometimes schools are happy to download this and print it off for you.
- 2) Complete Section 1: the Applicant part of the paperwork – pages 1-12.
- 3) Although you will have a detailed assessment report with a confirmed diagnosis, the NDIS application paperwork still requires pages 13-24 to be completed by a treating professional, such as a:

- GP
- Therapist
- Psychologist

Note: If you can't get a treating professional to complete the paperwork, you can still submit the application just with Section 1 and the assessment reports, and see if NDIS will accept it as is. They may however come back to you requiring the form to be completed.

- 4) When the application is ready to submit – scan and email it to: NAT@ndis.gov.au. Scanning and emailing it is a good option when you want to keep a record of the paperwork for yourself.
- 5) The NDIS is legally required to respond to the application within 21 days (according to NDIA Operational Guidelines). If you haven't heard by then, you can call them on 1800 800 110 to enquire as to the status of the application.

Some important things to note about accessing the NDIS:

For individuals with psychosocial (mental health) conditions, the NDIS has an "Evidence of Psychosocial disability" form on their website that professionals and support staff can complete.

A disability or psychosocial diagnosis alone doesn't guarantee eligibility or access with NDIS. The functional impact of the disability and the disability needs have to be clearly explained to ensure access.

In some cases, even without the finalised diagnosis, access to NDIS has been granted because of the clear documented evidence of permanent impairment against each NDIS functional life domain.

The 6 functional life domains that NDIS considers are:

- Social Interaction
- Self-Management
- Self-Care
- Communication
- Learning
- Mobility

If you are made eligible for NDIS, they will organise a Planning Meeting with you.

A Planning Meeting is where you need to detail your child's support needs and developmental goals relating to your child's disability that you would like support from the NDIS for.

To prepare for your NDIS planning meeting it is important to:

- 1) Complete a pre-planning workbook that will help you explore your child's needs and which goals you want to prioritise. This could take an hour or more, and it can be helpful to have someone go through it with you to give their thoughts and ideas. There are a few workbook options you may like to use:
 - NDIS Planning Booklet 2
 - Walking Along Side Me – Making your plan: Aboriginal Planning Workbook (older children)
 - My Child's Storybook – Aboriginal planning workbook through Positive Partnerships website

It is always best if you can ask the school or someone to scan the workbook once completed, so that it can be sent to NDIS before the planning meeting. You can email the workbook to enquiries@ndis.gov.au or to the email address provided on the Planning appointment email or letter. But be sure to include in the email the child's full name, date of birth, address and parent contact number so that NDIS can make sure they upload the document to the right person's record.

- 2) Make sure you have evidence or proof of the disability need where possible. For example, if you want behaviour support, ask your school for a letter detailing suspension information or behaviour issues at school to back this up. If you are asking for support for your child to attend special needs activities/groups you may want to get a response from a mainstream group that they feel your child would be better suited to a more specialist, supported group. If you are asking for a particular piece of equipment, get a price beforehand if possible and a letter from a therapist recommending the equipment.
- 3) Invite someone to come along with you as a support and to provide extra information to the Planner that you might forget to share. This could be a therapist, school staff member, friend or family member.
- 4) Think ahead of time whether you want to self-manage, Plan Manage or NDIA manage your child's plan. While self management gives the most flexibility, there are a lot of legislative and administrative requirements you need to meet and you can be audited at any time to make sure you are meeting them. To find out more about each, check out the NDIS website or ask your LAC or Planner.

How do I know what to ask for when I don't even know what supports are out there?

It can be tricky setting goals and asking for support when you don't know what services/supports are available. Your NDIS planner and LAC can help with ideas and suggestions as you give them more information about your child and their difficulties and needs. However, the following table gives ideas of some goals you may want to consider, and some of the supports that might be attached to it. But remember: NDIS funds only "Reasonable and Necessary" supports and they won't fund all requests, so be sure to prioritise your top few requests.

Example Goal	Example of supports possibly able to be accessed
For my child to develop their independence skills especially in getting ready for school in the morning and following an afternoon and evening routine.	<ul style="list-style-type: none"> • Occupational therapy to help with teaching skills and development of routines, visual systems for routines ... • Behaviour support to help with non-compliant behaviour • A support worker for older children to help consolidate independence skills
For my child to be able to develop their language, communication and social skills so they can better interact with others.	<ul style="list-style-type: none"> • Speech Pathologist for language • A Communication Device if needed • Social Skills groups/workshops • Parent training in the use of alternative communication methods • Support worker for older children to help with social skill development in different recreational and social settings
For my child (and me) to better learn how to regulate their emotions so there are less aggressive, behavioural incidents at home, in the community and/or at school.	<ul style="list-style-type: none"> • Positive Behaviour Support • Exercise Physiology to teach exercise and movement to manage aggressive emotions • Parent training in behaviour management • Qualified Gaming and Emotional Regulation Therapy/Groups Eg. Minecraft therapy; Roll for Growth
For my child to maintain their mobility and independence for as long as possible.	<ul style="list-style-type: none"> • Physiotherapy • Support to attend aquatherapy or other approved programs • Assistive Equipment
For my child to become completely independent in toileting.	<ul style="list-style-type: none"> • Continence products (pullups, bed protectors) • Disability Continence Program (like Pebbles)
To plan and prepare for post-school life including exploring employment options, getting a drivers license and move to independent living in the future.	<ul style="list-style-type: none"> • Disability Employment support • Microbusiness set-up support • Functional Capacity Assessment to determine independent living needs • Mentor/Support Worker to help with transition planning and independent skill building in required areas • OT assessment around driving; vehicle modifications etc.
For my child to have time away from family to decrease dependence on us and maintain carer capacity	<ul style="list-style-type: none"> • Supported disability camps during school holidays • Out of home short term stays
To have support in learning to navigate disability services, systems and setting up NDIS supports	<ul style="list-style-type: none"> • Support Coordinator to help with initial set up of NDIS Plan or Specialist Support Coordinator to help families with significant complexity requiring additional support exploring, coordinating and setting up multiple supports.

There are other supports and services you may also benefit from – for more information on any of the below, google search for their websites or speak to your LAC about whether you are eligible for them:

- Companion Card – photo ID giving free entry to activities for the support companion if the child has a severe permanent disability requiring constant support while in the community
- Country Age Pension Fuel Card – up to \$575 for fuel and taxi yearly if in eligible regional area
- Thermoregulatory subsidy - \$734/yr if meet qualifying conditions
- Acrod Permit – Available for people in wheelchairs, blind or with severe walking restrictions
- Kidsport - \$150 per year for eligible children 5-18 to participate in approved sporting clubs
- Kites Sensory Toybox library – over 4,500 therapeutic toys including the largest collection of switch adapted toys in the southern hemisphere.
- Joining Carers WA or Kalparrin for parent disability support and free events
- Join Be My Koorda for a culturally supportive parent run support group for Aboriginal families
- Exploring Young Carer (Sibling activities) through Carers WA
- Carer Gateway website which has: disability information; videos & free online training
- DDWA website (Developmental Disability WA) free resources to build advocacy skills
- Positive Partnerships offers workshops, webinars, an online learning hub & some great Aboriginal resources
- Early Days 0-6yo Autism training
- Carers WA e-learning – 9 short online courses on topics to do with NDIS and disability issues
- Consider joining disability support facebook groups, such as:
 - Kalparrin Families – connecting families of children with disabilities to share information, recommendations, ask questions to the collective etc...
 - NDIS Perth Support Workers – where some support workers advertise their skills and availability
 - Is There a Better Way – behaviour management for children with disabilities
 - Kalparrin Families sell buy donate – second hand therapy materials and equipment for sale