

My diary



limbs
 kids

The Kid's Diary for Children Living with Limb Loss



Making a real
difference together



Limbs 4 Life would like to thank our content contributors and valued donors for assisting with the costs of developing this publication.

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Introduction

Caring for a child living with limb difference can mean attending many meetings, making appointments, preparing applications, compiling historical records, sharing information, and collection of paperwork.

This diary has been developed to enable you to record questions you or your child may have, names and contact details of healthcare providers, your child's achievements and goals, and details about assistive technology needs. The diary will allow you to track changes over time and house information in one central place.

Throughout this diary there are tips and prompts to assist you to develop questions prior to attending a meeting, or after one has been held.

You may also find the diary a useful way of communicating information about your child to others who also care for your child, such as teachers, sporting coaches or family members. And it can also assist you when preparing applications or attending planning meetings with NDIS staff or NDIS-funded support providers.

This diary is available as a hard copy resource, and you are welcome to request or download additional copies as needed.



Support for children and young people with
limb differences and their families

About Limbs 4 Life

Limbs 4 Life is the peak body for people with limb loss/difference in Australia and works to provide information and support to people in the community. Through our Limbs 4 Kids program we support the limb loss community, and community stakeholders, by providing access to information and services such as:

- Limbs 4 Kids website
- Amplified Magazine
- Information Fact Sheets
- Limb Difference Fact Sheets
- Closed Facebook Groups - 'Amputees - Limbs 4 Life Australia' and 'Limbs 4 Kids'
- Peer Support

All of our resources are free. You can subscribe to receive free updates from Limbs 4 Life by visiting our website. The magazines and resources listed above can be downloaded from our website at www.limbs4kids.org.au or you can request hard copies by contacting Limbs 4 Life.

Limbs 4 Life provides access to Peer Support for people in the community prior to or following amputation surgery. Peer support is also available to parents or carers of children with a limb difference; whether that is before a baby is born, after an acquired childhood amputation or at any time throughout a child's life.



My personal, medical and health condition details

List details about your child's contact details, medical and health information, and devices used (e.g. prosthesis). You may want to have this information on hand when attending appointments or sharing details with others in your child's life.

Child's information			
Name			
Parents/carers			
Address			
Home phone		Mobile	
Language used			
Important things to know about me			

Medical information	
Diagnosis(es)	Age at time of diagnosis(es)
1	
2	
3	
4	
5	

Hospitalisations/surgeries/procedures	Date	Hospital	Doctor
Medications	Dose	Time	Supplements
Allergies	Reactions		

Notes

My Assistive Technology

Assistive Technology (AT) is the name for devices which help with your child's functionality and mobility. These may include: prosthetic devices; wheelchairs; crutches; walking aids; one-handed mouse; attachments (e.g. bike arms); and, vehicle modifications among other things. It's important to know which devices your child needs so they can be as active as possible.

When considering assistive technology needs you and your child should think about: family life; education; recreation and sporting activities; and, social life. This may mean speaking to your child's prosthetist, physiotherapist, occupational therapist, teachers or others. Speak to your child's healthcare providers about trialling different prosthetic options or other assistive technology devices so that the best possible outcomes can be achieved.

The following section will assist you to document information and record any questions you might have. Ask your doctor, prosthetic provider or other healthcare professionals to assist you in filling this out. Responses to these may also assist with NDIS planning, education, sporting or social group meetings too.



Prosthetic - components

Remember, because your child is growing they will need regular adjustments to their prosthesis. This may include new sockets, new feet and longer pylons to allow for any weight and height changes. Similarly, upper limb prosthetic users may require sockets (sometimes known as terminal devices) to accommodate different attachments (e.g. gym arm, fishing arm, bike riding arm etc).

In the table below you can write down details about your child's prosthesis.

Prosthetics
<p>My prosthetic device is made up of <i>(include details about components, brand, date prosthesis was received)</i></p>
<p>My suspension system is <i>(include the brand and size if relevant)</i></p>
<p>Other questions</p>

Prosthetic - questions

You may have some questions after your child receives their first or subsequent prosthesis. The questions below are only a guide. If you have other questions write them down so that you ask these at your next appointment or before taking your child's prosthesis home.

How many hours per day should my child wear their prosthesis for?

What should I do if the prosthesis is causing my child pain?

What should I do if my child's prosthesis feels loose and unsafe?

Tip: Kids are active and it is not unusual for them to break their prosthesis. If you are in the process of developing your child's NDIS Plan make sure you include repairs and maintenance in under their Capital Supports funding area.

Who should I contact if my child's prosthesis is leaving marks on their skin?

Will your child's prosthetist contact you to make a follow-up appointment or do you need to contact them?

What do I do if my child cannot wear their prosthesis?

Other questions



Other Assistive Technology

Depending on your child's type of limb difference, their goals and/or any other health issues may mean they need additional assistive technology. For example, a child with a lower limb difference may need a wheelchair or crutches to assist with mobility. Or, a child with an upper limb difference may benefit from equipment (such as personal aids or information technology) to assist in the home, school or community. Older children may also be considering new transitions, such as learning to drive with a modified vehicle.

The questions below are only a guide. But hopefully they will assist you when preparing questions to discuss with your child's healthcare providers. Responses may assist with NDIS planning, education, sporting or social group activities too.

Assistive Technology – lower limb difference
Does my child need aids for showering or for use in wet areas?
Does my child need a set of crutches?
Does my child need a wheelchair or other mobility aids? If so, what type will suit my child's needs and goals?
Other?
Assistive Technology – upper limb difference
Does my child need a book holder or page holder to help with schooling?
Does my child need an iPad or a computer with voice recognition technology?
Does my child need assistive devices to help with eating or drinking or dressing?
Other ideas: Sloped desktop, pencil grips, swim fin for swimming, automatic toothpaste dispenser.

Getting to know me

Provide information so that medical, allied health, funders and educators understand your child's unique strengths, skills, challenges, community engagement activities, ways your child likes or doesn't like to be assisted, and assistive technology used.

Tip: Attach your NDIS 'About Me' to this page and include your three goals.

My name		Nickname	
Date of birth		Today's date	

A little about me

My strengths (things that are easy for me, that I enjoy and I'm good at)

My challenges (things I find difficult some or all of the time - e.g. mobility, energy, communication, behaviour, feeding)

My community (e.g. school, sports, groups, religion, parks, play centres)

Ways you could help me

Things I don't like

Other things I would like to share with you

Tip: Information about your child is likely to change over time, so consider updating this page as required. You might find that it is a good record of how your child is developing and changing over time too!

My goals

Use this to record goals that your child would like to work towards. The goals may be short, medium or long-term and can assist in planning, keeping motivated and setting realistic future plans. Your child's healthcare team, or other supporters, may ask about goals so they can assist in setting them and identifying what might be needed to achieve these.

For example: Chris wants to play cricket and would like to join the local club but is concerned he won't be able to keep up with his team members. Chris would like to play competitive cricket within the next three months. Chris needs a lower limb prosthesis which enables him to run while batting and standing comfortably for long periods of time. The family plans on discussing his prosthetic needs, so that he can participate to the best of his ability.

Goals and how I am going to achieve them	By when

Tip: Remember that you can trial different prosthetic options (e.g. feet, knees and blades). Speak to your prosthetic provider about options.

My achievements

Use this to record your child's achievements and accomplishments. It's a great way of reviewing your child's successes over time.

For example: *On the 12/4/2019 Amanda learned to ride her bicycle using her upper limb bike arm attachment. The advice from the occupational therapist really helped us to understand how Amanda should wear her arm and attach it to the handlebars. It took Amanda three attempts before she felt confident to ride on her own.*

Date	Achievement

Date	Achievement

Tip: Consider taking photos of your child reaching a personal achievement. You may even want to print a copy of any photos and staple these here.

My healthcare providers

List contact information for different healthcare providers your child sees (e.g. doctors, prosthetist, occupational therapist, physiotherapist, psychologist).

Healthcare Provider	
Name	Position
Phone	Email
Appointment date	
Other information	

Healthcare Provider	
Name	Position
Phone	Email
Appointment date	
Other information	

Healthcare Provider	
Name	Position
Phone	Email
Appointment date	
Other information	

Healthcare Provider	
Name	Position
Phone	Email
Appointment date	
Other information	

Tip: consider stapling business cards of healthcare providers to this page.

Appointments Log

Medical and Allied Health

Use this to record appointment outcomes and schedule future ones.

For example: *On the 3/2/2020 we attended ABC Prosthetics and saw our prosthetist Amanda Jones. The appointment was to make a cast for a new prosthesis for Jamie. The next appointment is scheduled for the 11/2/2020 to try the new socket.*

Date	Provider/Clinic	Reason for appointment/ care provided	Next appointment	Clinic phone number

Tip: Record information and appointments in your phone or computer calendar.

Date	Provider/Clinic	Reason for appointment/ care provided	Next appointment	Clinic phone number

Appointments Log

Hospital Admissions

Use this to record hospital admissions.

For example: *On 9/11/2019, Mary attended XYZ Children's Hospital (emergency room) after having a severe asthma attack. Dr Smith discussed a treatment plan and we were advised to see our GP for ongoing follow-ups and potential referral to a specialist.*

Date	Hospital or emergency room	Reason for admission	Notes

Appointments Log

National Disability Insurance Scheme (NDIS)

Use this to record meetings or phone calls with NDIS staff, Local Area Coordinators, Planners and providers of NDIS-funded supports.

For example: *On the 15/1/2020 we met with John a Local Area Coordinator at ABC (9888 7777). The reason for the appointment was to have an NDIS Plan Review, with our next appointment scheduled on the 15/1/2021.*

Date	NDIS Provider	Reason for appointment	Next appointment	Provider phone number

Date	NDIS Provider	Reason for appointment	Next appointment	Provider phone number

Funding for Assistive Technology and Supports

People are often concerned about the costs associated with prosthetic limbs and other forms of assistive technology. If your child is an Australian citizen, or permanent resident, the following funding applies:

National Disability Insurance Scheme (NDIS):

The NDIS funds the costs associated with prosthetic devices, assistive technology and other supports if a person has a disability and is deemed eligible. The type of supports your child may receive depends on their goals and outcomes.

For more information visit: www.ndis.gov.au

Insurance funding:

If a child's limb loss resulted from a motor vehicle accident or other circumstances they may be eligible for funding outside of the NDIS.

Notes

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