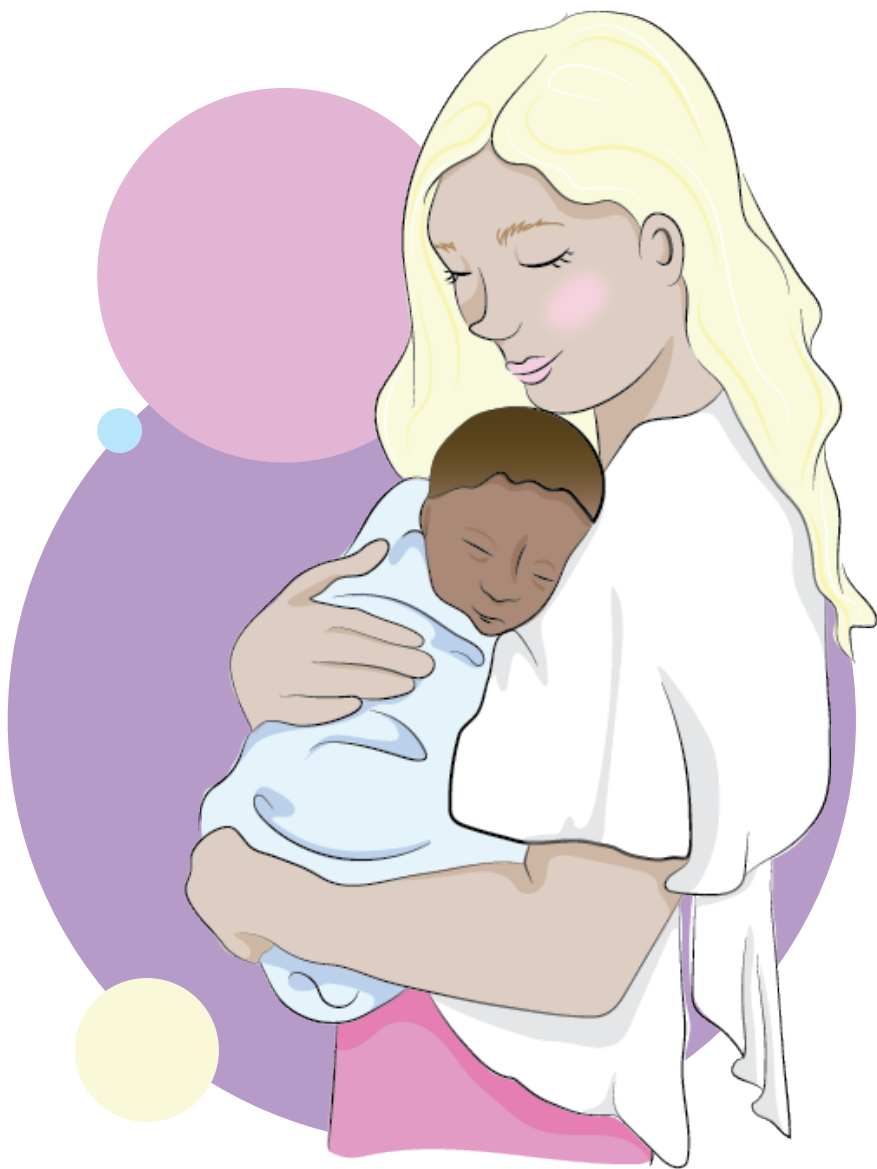


Parenting After Polio

Quick tips for parents



This booklet has been designed for parents; someone who is or may be planning to be a parent, or someone in this age bracket who has had polio. It has been created to support parents in their journey throughout pregnancy, birth, and baby-care. It outlines common issues faced by mothers who have had polio, and the supports available in Melbourne.

This document has been created by Gabrielle Longden and Ellie Cassels-Zeira. This project was spearheaded by Nimo Hersi, a disability advocate and mother of two children, who has had polio; together with Denise Currie from Polio Services Victoria at St Vincent's Hospital Melbourne; and Steph Cantrill from Polio Australia. The information contained within has been gathered from healthcare literature and the voices of mothers who have had polio. Illustrations by Teggun Orth ©2020.

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Contents

BACKGROUND	4
What we want to avoid:	4
What we want to foster:	4
COMMON ISSUES FOR PARENTS POST-POLIO IN PREGNANCY, BIRTH AND BABY-CARE TASKS	5-6
Mothers' Suggestions for Overcoming these Issues	6
COLLABORATION	7-9
Health Professionals	7-8
National Disability Insurance Scheme (NDIS)	8
Advocacy Supports	8
Polio-Specific Supports	9
Health Translation	9
KEY THINGS TO KNOW	10-11
Early Planning	10
Institutional Discrimination	10
Advocacy	10
Disability Disclosure	10
NDIS Considerations	11
Language Considerations	11
Peer Support	11
KEY CONTACTS	12
Advocacy Supports	12
NDIS Local Area Coordinators	12
Polio-Specific Supports	12
Other	12
REFERENCES	13

Background

Polio in the Australian context is changing. While there has not been poliovirus transmission detected in Australia since the 1970s, transmission has continued beyond the 1970s in many nations¹. A new generation of polio survivors is migrating to Australia from countries, including but not limited to Afghanistan, India, Nigeria, Pakistan, Somalia, Vietnam and Russia. The Australian healthcare system is learning and adapting to meet the needs of parents and parents-to-be who have had polio.

Polio can have lifelong effects². We are mindful that cultural perspectives on the history of polio and the possible effects may vary. In the same way, we acknowledge that each person has a unique experience of polio and the responses of society and healthcare systems.

What we want to avoid:

- Negative healthcare experiences which may impact the joyful nature of birth and parenting.
- Any form of discrimination, including racial, gender, or disability discrimination.
- Anxiety or unnecessary stress as a result of miscommunication or unpreparedness.

What we want to foster:

- Positive and enjoyable pregnancy, birth, and parenting experiences.
- Teamwork and communication between parents and healthcare professionals to meet the needs and wants of parents.
- The independence of parents relating to their health and parenting roles.
- For parents, polio survivors, migrants, and refugees to understand and exercise their rights within and beyond the healthcare system.
- Further growth within the healthcare system to provide service and support to the highest standard.

Common Issues for Parents Post-Polio in Pregnancy, Birth and Baby-Care Tasks

Mothers who have had polio commonly report experiencing these issues during pregnancy, birth, and in baby-care tasks:

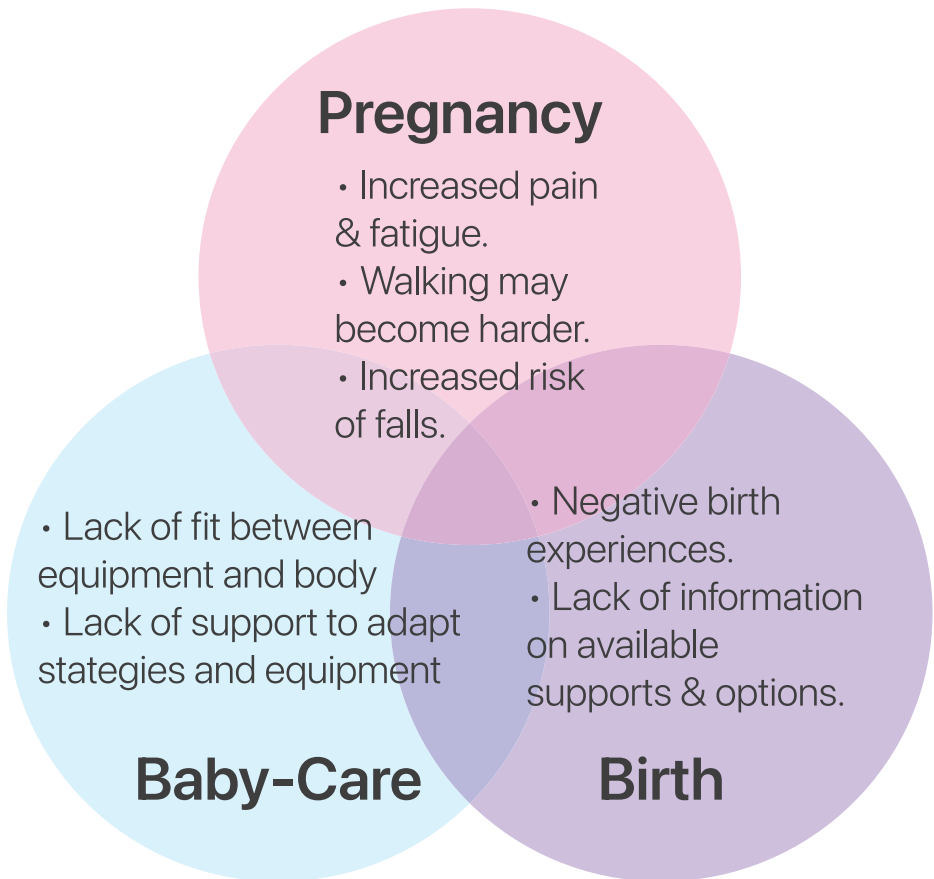


Figure 1: Common issues for parents post-polio in pregnancy, birth and baby-care tasks

Mothers’ Suggestions for Overcoming these Issues

Table 1: Common recommendations reported by parents and health care professionals.

Pregnancy	Birth	Baby-care
<ul style="list-style-type: none">• Talk to your GP and physiotherapist about changes to pain and fatigue.• Talk to your GP, orthotist, and NDIS coordinator about your pregnancy and the supports you would like.• If you do not have an NDIS plan contact an NDIS local area coordinator to help you prepare one.	<ul style="list-style-type: none">• Talk to your Dr. and physiotherapist about changes to pain and fatigue.• Talk to your Dr., orthotist, and NDIS coordinator about your pregnancy and the supports you would like.• If you do not have an NDIS plan contact an NDIS local area coordinator to help you prepare one.	<ul style="list-style-type: none">• Connecting with an occupational therapist and a social worker early in pregnancy can help to prepare for baby-care tasks, including access to equipment, funding, and strategies before birth³⁻⁵.• Adapting traditional baby-care equipment to suit your needs³⁻⁵.

Collaboration

Collaboration is key. Communication between parents and health professionals means planning, preparation and resource sharing is appropriate and timely⁶. It also helps each person involved to have a clear understanding of their role and responsibilities at each stage of pregnancy, birth, and baby-care. Overall, parents and health professionals share one goal: a positive pregnancy, birth, and parenting experience.

Table 2: List of key supports through pregnancy, birth and baby-care

Supports in your parenting journey		
<ul style="list-style-type: none">• GP• WIN clinic• Midwife• Obstetrician• NDIS• Occupational therapist	<ul style="list-style-type: none">• Social worker• Orthotist• Physiotherapist• Diversity & Disability Program• Refugee Health Service• Centre for Culture, Ethnicity & Health	<ul style="list-style-type: none">• Maternal child health nurse• Polio Services Victoria at St Vincent’s Hospital, Melbourne• Polio Australia• Post Polio Victoria• Polio Network Victoria



Health Professionals

GP - *Pregnancy*

A GP is often the first point of contact for new parents. They can confirm pregnancy, facilitate antenatal planning, and perform a general health assessment which may be an opportunity to highlight healthcare needs. GPs can provide recommendations, referrals, and assist NDIS applications.

Women with Individual Needs (WIN) Clinic – *Pregnancy, birth, baby-care*

The WIN Clinic (at the Royal Women's Hospital) provides individualised pregnancy care and one-to-one childbirth and parenting information with the aim of helping you to independently care for your baby. The clinic has a midwife and social worker with experience in disabilities post-polio and can work together with you to identify which services and supports and/or assistance you may require.

Occupational Therapist – *Pregnancy, birth, baby-care*

Occupational therapists can provide advice and training relating to baby-care by prescribing or adapting equipment to support these tasks. They can assess and adapt the home environment to support parents during and post pregnancy, support fatigue management, advocate for parents during pregnancy, birth, and in baby-care, and prepare reports for NDIS funding.

Social Worker - *Pregnancy, baby-care*


While varied depending on the service provider, the role of a social worker is to locate and link parents with appropriate supports, services, funding avenues, and resources.

Orthotist – *Pregnancy, baby-care*

Orthotists are uniquely qualified to prescribe, design, fit and monitor orthoses to facilitate mobility and posture. Orthotists are especially involved with designing and adapting supports as bodily changes occur during pregnancy and post-birth.

Physiotherapist – *Pregnancy, birth, baby-care*

Physiotherapists can address pain, posture, falls risk, fatigue management, and joint/limb instability associated with a changing centre of gravity during pregnancy.



Health Professionals

Maternal Child Health Nurse - *Baby-care*

The role of the maternal child health nurse is to support, assist, and nurture the well-being of you and your child in the postnatal period, and to refer to appropriate agencies in the local community as needed. If you require enhanced support during the postnatal period to perform baby-care and daily living tasks, enhanced maternal child health nurses can be arranged to provide extra care.

NDIS - *Pregnancy, baby-care*

The National Disability Insurance Scheme (NDIS) can provide eligible parents who have had polio and have a disability funding for equipment and modifications to assist in all areas of pregnancy, birth, and the early months of baby-care. If you think you may be eligible and do not already have an NDIS plan, you can contact your local area coordinator (LAC) who can help you to navigate the NDIS, assist in identifying your goals, and develop your plan. There are two local area coordinators in Melbourne:

- The Brotherhood of St Laurence supports people who reside in the Bayside Peninsula, Hume Moreland, North Eastern Melbourne, Western Melbourne, and Brimbank Melton areas
- LaTrobe Community Health Service can support people residing in Outer Eastern Melbourne, Southern Melbourne, and Inner Eastern Melbourne.

Advocacy Supports

Diversity & Disability (DnD) Program - *Pregnancy, birth, baby care*

DnD is a self-advocacy program for migrants with disabilities living in Victoria, supporting people to speak for themselves and achieve their full potential as valued citizens of the community. Delivered through the Migrant Resource Centre, North West Region Inc., DnD provides workshops and one-on-one support to enhance the freedom, independence, knowledge and opportunities of migrants with disabilities.

The Southern Migrant & Refugee Centre – *pregnancy, birth, baby-care*

The Southern Migrant and Refugee Centre can support women from refugee / CALD backgrounds who have arrived in Australia within five years and live in the local government areas of Dandenong, Casey, and Cardinia. Their service is provided by workers who are bi-or multilingual and can include connecting pregnant women and mothers with relevant support services and advocacy throughout the NDIS application process.

Advocacy Supports

Refugee Health and Wellbeing – *Pregnancy, birth, baby care*

Refugee Health and Wellbeing is a service provided by Monash Health which aims to enhance access, quality of care, and care coordination for refugees and asylum seekers. The Nurse on Triage service is available to parents to facilitate understanding of which health professionals can support their needs.

Polio-Specific Supports

Polio Services Victoria (PSV) at St Vincent's Hospital Melbourne - *Pregnancy, birth, baby-care*

PSV works collaboratively to provide information and education to parents and health professionals regarding specialist assessment, health planning, equipment applications, and referrals to appropriate services.

Polio Australia – *Pregnancy, birth, baby-care*

Polio Australia is a national peak body committed to providing advocacy, advice, education and support to enhance the quality of polio information and service provision for polio survivors.

Post Polio Victoria (PPV) – *Pregnancy, birth, baby-care*

PPV is a not-for-profit membership based organisation run by a volunteer management committee. It advocates for polio informed health services and to ensure polio survivors have equitable access to opportunities within the community.

Polio Network Victoria – *Pregnancy, birth, baby-care*

Polio Network provides support to polio survivors, carers, families, and health professionals across Victoria. They are a central hub to the numerous supports available for polio survivors across the lifespan.

Health Translation

Health Translation is a free, government-funded service linking service providers to multilingual health resources produced in Australia. Resources are published by government departments, peak health bodies, hospitals, and community health and welfare organisations.

Key Things to Know

Early Planning

Knowing which health professionals can support you and connecting with them early in your pregnancy has been recommended by mothers who have had polio. These mothers report that this has helped them to put NDIS funding plans in place, manage pain and fatigue, and prepare for baby's arrival (including feeding, bathing and changing).

Institutional Discrimination

Access to positive healthcare without discrimination is a fundamental right of every human being regardless of race, gender, ability, religion or political belief, or economic or social state⁷⁻⁹. Parents are supported by national and local policies and legislation including:

- The Australian Human Rights Commission Act 1986
- The Racial Discrimination Act 1975
- The Sex Discrimination Act 1984
- The Australian Government's Social Inclusion Initiative
- The Multicultural Access and Equity Policy

Parents should seek support from relevant advocacy services if they have concerns that they are or may be discriminated against.

Advocacy

Parents should be able to expect advocacy from every health professional and disability advocacy service. Advocacy can support your understanding of your rights in regards to birth choices, baby-care, parenting, discrimination, and disability³. There is strength in numbers and having the support of a health professional or disability advocate may help your voice to be heard and your choices to be respected.

Disability Disclosure

The more health professionals are aware of your health history, the more they can tailor their services to support your needs and wants. If you have migrated to Australia or are from a refugee background, it is important to understand the Australian health system may not have a record of your medical history. It is also important to consider how much experience health professionals in Australia have had with polio survivors. Parents may need to act as their own advocates or engage the help of an advocacy service to continue supporting the education of health professionals in the Australian health system about the history of polio, the effects of polio, and the unique impact this has on parents.

Key Things to Know

NDIS Considerations

It is important to have NDIS funding plans in place before the birth of your baby so that you can have access to any necessary baby-care support. Health professionals can provide referrals to support the application process and development of funding plans. The earlier funding is in place, the earlier preparation can be made to ensure the best supports for you as a new mother / parent. If you already have an NDIS plan, consider updating it to support you throughout pregnancy and postnatally. If you do not already have a plan, talk to your NDIS local area coordinator about applying for one.

Language Considerations

You may feel or have the experience that health professionals do not understand your unique experiences with polio and the health system. You may need to be patient with health professionals as they learn what polio means within a modern Australian context and what the effects of polio may mean for young polio survivors and people of CALD background. If you would like further support, contact an advocacy service to speak to your healthcare provider together or on your behalf.

Peer Support

Peer support is the advice and support parents may receive from other polio survivors, migrant /refugees, or parents. This can come in many forms: websites, Facebook groups, polio and post-polio support networks, or local community groups. Some examples include:

- Polio Australia
- Post-Polio Victoria
- Polio Network
- Post-Polio Coffeehouse Facebook group

Social workers and disability advocates may also be able to link parents to appropriate support networks. Parents are busy and technology is advancing, meaning not every peer support requires consistent face-to-face contact.



Key Contacts

Advocacy Supports

Disability and Diversity Program

T: 9367 6044

E: christian@mrcnorthwest.org.au

North West Migrant Regional Centre

E: mrcnw@mrcnorthwest.org.au

W: www.mrcnorthwest.org.au

The Southern Migrant & Refugee Centre

T: (03) 97671900

E: smrc@smrc.org.au

W: www.smrc.org.au

NDIS Local Area Coordinators

Brotherhood of St Laurence

T: 1300 275 635

E: ndis.info@bsl.org.au

W: <https://ndis.bsl.org.au>

Latrobe Community Health Service

T: 1800 242 696

W: <https://www.lchs.com.au>

Polio-Specific Supports

Polio Network

W: <https://www.polionetworkvic.org>

Post Polio Victoria

T: 0431 702 137

E: info@postpoliovictoria.org.au

W: <https://www.postpoliovictoria.org.au>

Polio Services Victoria at

St Vincent's Hospital Melbourne

Monday to Friday, 8:30am-5:00pm

T: (03) 9231 3900 or 1800 0330 324

E: psv@svha.org.au

W: www.psv.svhm.org.au

Other

FARREP Clinic

Monday to Friday, 9:00am-5:00pm

T: (03) 8345 3058

E: farrep.program@thewomens.org.au

Women with Individual Needs

(WIN) Clinic

T: (03) 8345 2159

W: <https://www.thewomens.org.au>

Health Translation

W: <https://www.healthtranslations.vic.gov.au/bhcv2/bhcht.nsf>

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- ⁷ Anti-Defamation League. (2017). *Understanding and challenging ableism*. <https://www.adl.org/education>
- ⁸ Raising Children Network. (n.d.). *Anti-discrimination laws in Australia*. <https://www.raisingchildren.net.au>
- ⁹ Australian Human Rights Commission. (2012). *Access to health services for people with disabilities*. <https://www.humanrights.gov.au>



We acknowledge the Boon Wurrung & Wurundjeri people, Traditional Owners of the land we work on, and pay our respects to their Elders past, present, and emerging.

We support the Uluru Statement from the Heart to achieve justice, recognition and respect for First Nations people and we accept the invitation contained in the Statement to walk together with Aboriginal and Torres Strait Islander peoples in a movement of the Australian people for a better future.

