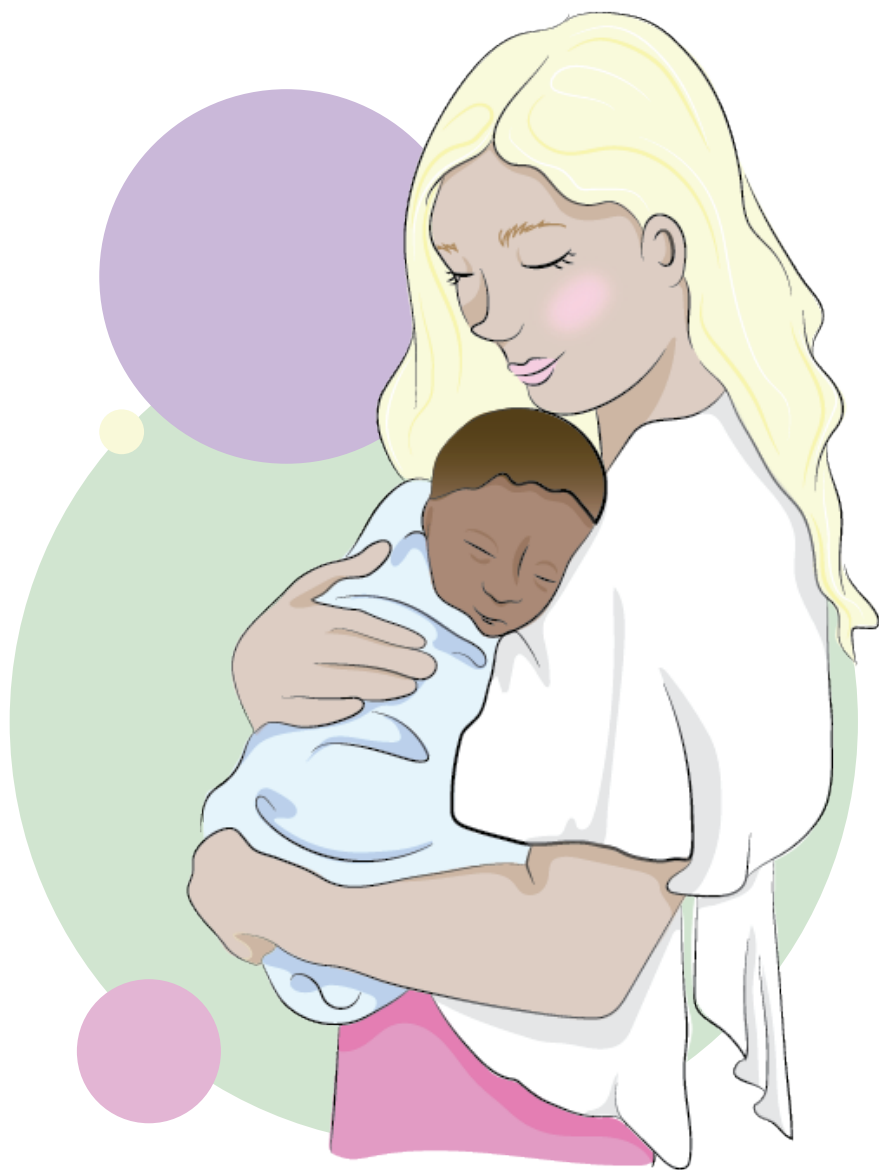


Parenting After Polio

A quick guide for health professionals



This booklet has been designed for healthcare professionals who may have contact with a parent; someone who is, or may be planning to be a parent, or someone in this age bracket who has had polio. Due to the prevalence and geographic distribution of polio, this person is more than likely to be from a migrant or culturally and linguistically diverse (CALD) background¹. Information herein supports healthcare professionals to understand the issues commonly experienced by this community and to outline available supports.

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 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, professionals, and the voices of mothers who have had polio. Illustrations by Teggun Orth 2020 ©. These illustrations may not be reproduced without permission (teggunashleigh@icloud.com).



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Background

The context of polio in Australia is changing. While there has not been poliovirus transmission detected in Australia since the 1970s, in many countries around the world virus transmission has continued for decades beyond the 70s¹. The average age of polio survivors in Australia is actually decreasing as this new generation of polio survivors migrate to Australia from around the world. The Australian healthcare system must learn and adapt to meet these survivors' needs as parents and parents-to-be.

About Polio

- It can cause lifelong disability and presents differently in each person².
- Common impacts include muscle weakness, paralysis and pain. However, the person who has had polio is the best person to describe their ability and where they need support.
- Experiences of polio and post-polio effects can be challenging and may be associated with feelings of shame or other psychological impacts which vary between individuals.
- Healthcare should emphasise the retention of ability rather than improving ability³.

The New Generation of Australian Polio Survivors

- Disability is interpreted differently depending on cultural background. This means the person you are working with may have different beliefs and attitudes towards polio.
- The new generation of polio survivors may have migrated from countries, including but not limited to, Afghanistan, India, Nigeria, Pakistan, Russia, Somalia, or Vietnam¹.
- English may be a second, third, or fourth language. Providing information in English without an interpreter may not be appropriate.
- Being of CALD background and having a disability means this community may have experienced stigma and discrimination. This and other factors may contribute to a power imbalance in the healthcare relationship.
- The parent may be unaware of their rights in Australia⁴.

What 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 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 Experienced by Parents in Australia Post-Polio

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

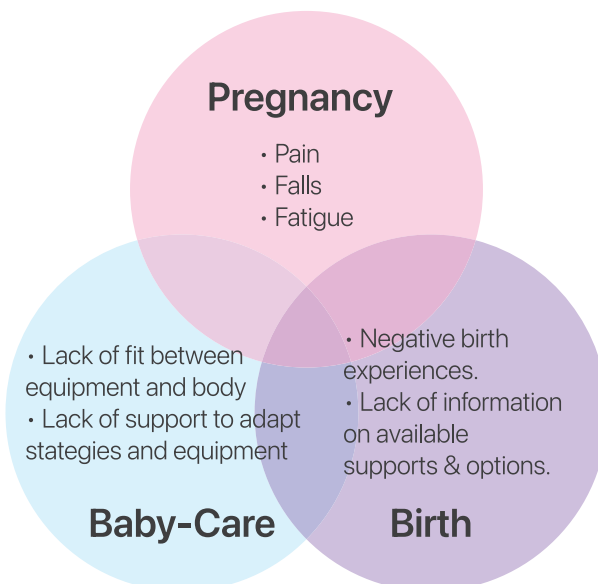


Figure 1: Common issues for parents post-polio in pregnancy, birth and baby-care tasks



Supporting Parents Who Have Had Polio

Considering the unique experiences of Australia’s new generation of polio survivors, the following recommendations are key to healthcare professionals and services providing relevant and quality maternal care:

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

Pregnancy	Birth	Baby-care
<ul style="list-style-type: none">• Ask about pain, fatigue and how the effects of polio are impacting pregnancy⁵.• Ask about whether the person has an NDIS plan and would like supports for funding.• Support the person to complete an NDIS application or refer them to advocacy services or their NDIS Local Area Coordinator for support.	<ul style="list-style-type: none">• Provide information on available birth options.• Advocate for mothers to birth the way they want to and refer them to relevant advocacy services if required⁶.	<ul style="list-style-type: none">• Describe the role of occupational therapists and social workers in supporting parents to prepare for baby-care tasks, including access to equipment, funding, and strategies⁷.• Refer to appropriate services (including occupational therapy and social work) in early pregnancy⁷.• Describe the role of polio specific services (Polio Australia or St Vincent’s Polio Services) and provide referral information.

Collaboration

Collaboration and early referral, assessment, and preparation are key to relevant and quality healthcare when working with this community of parents⁸. Effective communication between stakeholders facilitates resource sharing, planning, and preparation. Key to this process is ensuring healthcare professionals understand the roles of relevant stakeholders in supporting this community throughout pregnancy, birth, and baby-care.



Table 2: List of relevant stakeholders

Key Stakeholders

- | | | |
|--|--|--|
| <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 between parents and the healthcare sector; confirming pregnancy, facilitating antenatal planning, and performing general health assessments which may be an opportunity to highlight healthcare needs. GPs play a vital role in education and referral.

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

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

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 the 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

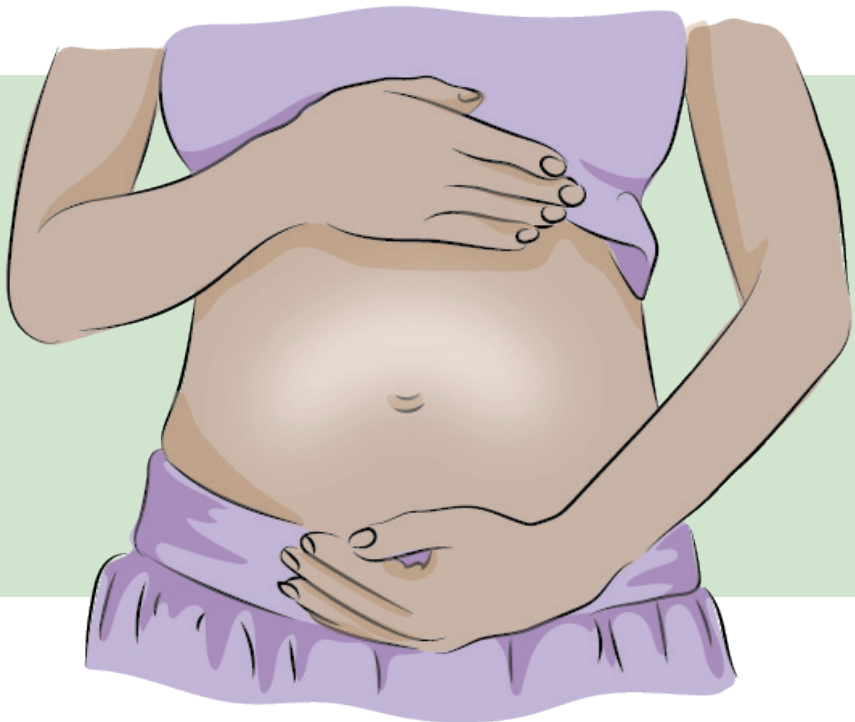
Maternal Child Health Nurse - *Baby-care*

The maternal child health nurse supports, assists, and nurtures the well-being of the mother and child, and refers to appropriate agencies in the local community as needed. Where enhanced support is required postnatally, enhanced maternal child health nurse services can be accessed.

NDIS - *Pregnancy, baby-care*

The NDIS can provide eligible parents who have had polio and have a disability with funding for equipment and modifications to assist in pregnancy, birth, and the early months of baby-care. To support mothers who do not already have an NDIS plan, you can refer them to their local area coordinator (LAC) who can help them to navigate the NDIS, assist in identifying their goals, and develop their plans. 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 which supports 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. You can refer parents to DnD if you feel they may benefit from advocacy services.

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 daily to facilitate where and how to make appropriate referrals. You can contact or refer to the nurse on triage service to improve healthcare for parents who may be refugees or asylum seekers.

Centre for Culture, Ethnicity & Health (CEH) - *Pregnancy, birth, baby-care*

CEH works with services to provide training in cultural competency, understanding the NDIS, and health literacy. The CEH website provides links to a resource hub with relevant information regarding migrant and refugee health, disability in CALD communities, health translations, and using language services.

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

The Southern Migrant and Refugee Centre can support women from refugee / CALD backgrounds who 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.





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 the state of Victoria. They are a central hub to the numerous supports available for polio survivors across the lifespan.

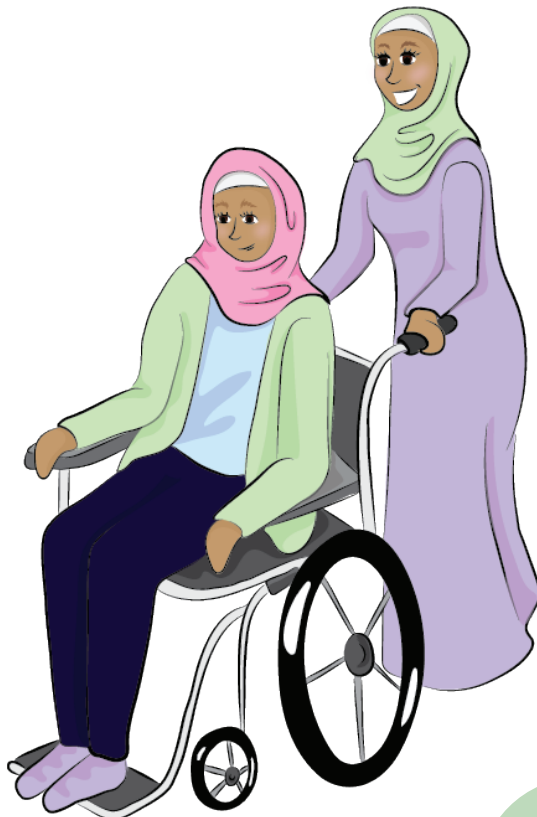
Health Translation

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.

Early Referral, Assessment and Preparation

Preventative care is always best. Early and wholistic referral, assessment and preparation are key. Some things to consider:

- Identify and prepare for all needs and wants of the parent by linking them to the right people at the right time⁹.
- Receive timely advice from supporting specialist services (e.g. Polio Services Victoria at St Vincent's Hospital Melbourne).
- Ensure early referral to allied health services (e.g. occupational therapy and social work) for the prescription of equipment and provision of education regarding baby-care tasks (e.g. feeding, bathing, changing, carrying)¹⁰.
- Assistive technology/equipment or adaptations need to be available at the appropriate time, considering manufacturing, wait-times, and approval times^{7 10}.
- NDIS funding application processes – whether first-time applicants or renewing plans already in place – should be up-to-date and available before birth.



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 state^{6 11 12}. Parents with polio 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

Healthcare professionals should provide relevant information and advise parents to seek support from relevant advocacy services if they have concerns that they are or may be discriminated against.

Referrals to the WIN Clinic

When referring to the WIN Clinic it may be important to consider the following:

- When describing the service, avoid language such as 'specialist service' or 'disability service'. This language may not be received well from parents who do not identify as having a disability.
- Encourage parents to meet directly with the WIN Clinic to gain an understanding of the services and supports they provide from pregnancy to early baby-care needs.

DHHS

It is important for health professionals to acknowledge any anxiety parents may feel regarding the DHHS, and to then work to relieve that anxiety. This has been highlighted in literature and anecdotal accounts of parents who have had polio^{5 8}. It may also be appropriate for health professionals to mark the boundaries of their profession's responsibility in reporting and assessment, making these clear to both the DHHS and parents as needed.

Key Things to Know

NDIS Considerations

- Ensure plans are in place before birth to fund baby-care needs.
- If the mother-to-be does not already have an NDIS plan, connect her with her NDIS local area coordinator and relevant advocacy group who can support her to prepare an NDIS application.
- Each health professional needs to understand their role in NDIS applications and, if uncertain, seek advice accordingly.
- In preparing support for NDIS applications, language should emphasise the effects of the parent's disability and their environment on performing the tasks they need and want to do in pregnancy and baby-care.
- To be eligible for the NDIS, parents need to be Australian citizens and have a significant and permanent disability. Some parents may be hesitant to acknowledge their history of polio and any resulting disability.

Advocacy

It is the role of every health professional to advocate for the parents they provide care to. This may involve educating other health professionals, healthcare systems, or the parents themselves⁷. Advocacy should include education and support regarding choice, the effects of polio, and the rights of parents in relation to discrimination, disability, and parenting⁷. Disability advocacy services can further support this role.

Disability Disclosure

It is important to be aware that some parents may be hesitant to acknowledge their history of polio, and any resulting disability. Additionally, as new migrants, some parents may not present to health services with a medical history. Regardless, it is the responsibility of each health professional to perform an holistic assessment and provide collaborative healthcare which supports the individual needs and wants of the parent.

Language Considerations

- Language used gives parents insight into the health professional's understanding of their unique wants, needs, and history.
- Consider using phrases such as 'to retain function', rather than 'to get stronger'.
- It is important to be mindful that making time to build rapport with parents will encourage confidence in healthcare professionals.

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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- ¹² 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.

