

The background is a solid red color with a repeating pattern of light-colored, stylized floral and leaf motifs. At the bottom of the page, there is a white silhouette of a person's head and neck, facing right, which is partially cut off by the bottom edge of the page.

HOPE

A guide to surviving bed-rest

Bed rest is in many cases a necessary and important part of medical care. Most pregnant women benefit from being active and have no need for extended bed rest. In the field of preterm birth prevention, however, a small number of women may benefit from time spent lying horizontal as it may relieve pressure on the cervix. For these women, the guidelines in this booklet provide invaluable advice as to how they can manage when needing to spend extended periods of time confined to bed.

The Western Australian Preterm Birth Prevention Initiative is pleased to support the release of these guidelines and we are confident they will be of benefit for those women needing this form of medical care.

Professor John Newnham AM
Chair, The Western Australian Preterm Birth Prevention Initiative

Disclaimer

This guide has been written by parents who have themselves experienced bed-rest. It is not intended as professional advice, and should not be relied upon as a substitute for consultations with qualified professionals who can determine your individual needs.

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If you are reading this booklet, congratulations on your pregnancy and we **HOPE** you go the whole nine months.

If you are at risk of premature delivery, you may have been advised to go on bed-rest. This can vary from modified bed-rest where you spend most of your day resting, but can get up for meals and potter around the house, to strict bed-rest where you are not even allowed to go to the bathroom and you may lie inclined with your feet higher than your abdomen. You may be allowed to stay at home, or need to be monitored closely at hospital.

Bed-rest is hard! All of a sudden you are no longer able to work or care for your family. Your pride has to be swallowed. You may find it difficult to concentrate. After a couple of weeks, your muscles will start to weaken, you may feel dizzy if you stand for too long, your fitness will disappear. All the while you are concerned about your unborn baby's health.

Personally, I struggled during my 3½ months of strict bed-rest. My husband and I felt that none of our family or friends really understood what we were going through. I couldn't find anyone to provide relevant emotional or peer support. I cried many tears. I was scared for my unborn son. I was worried about my 9-year-old son. I felt alone. I learnt to stare out the window for hours on end.

Without adequate support and coping mechanisms you may feel like your world is crumbling around you. This booklet is about giving you some ideas to make your journey easier. It is also a source of hope with some inspirational stories sharing some of WA's own tiny sparks. My youngest son Blake is included here.

On behalf of Tiny Sparks WA and the community supporting us, we wish you the best of luck in the remainder of your pregnancy. You are amazing!

Bronwyn Rose

Co-Founder and Chairperson, Tiny Sparks WA

Blake



Photo Credit: Amber Bates Photography

Mum Bronwyn suffered Preterm Premature Rupture of Membranes (PPROM) also known as waters breaking early at 15 weeks gestation due to amniocentesis with a full rupture at 26 weeks. She was prescribed Erythromycin (antibiotics) at 15, 19 & 26 weeks and steroids at 26 weeks. After 2 ½ months strict bed-rest at home plus 1 month hospital bed-rest, Blake was born at 29 weeks, 5 days gestation weighing 1315g. He came home after a 60 day NICU/SCN stay. He is now 4 years old, developmentally on track, a healthy and very determined young man.



1. Understand your medical condition

It may be that you have never heard of your condition before or if you have, you don't know much about it. As the old saying goes "knowledge is power". The more you understand about your medical condition, the more you will understand the symptoms you are experiencing. Ask your doctor for resources on your particular condition, and remember, you should always call your doctor if you have any concerns. You may wish to keep a notepad to jot down any questions you may have.

Understand exactly what you are, and are not allowed to do. Whether you are allowed to shower, go to the toilet, eat at the dining table or sit upright. Whether you can continue to work. Whether you can walk from the car to your doctor's office or need a wheelchair.

Ask your doctor how to avoid deep vein thrombosis (DVT). The use of compression stockings or doing ankle and leg exercises may be advised. Please ensure that you don't undertake any exercise unless directed by your doctor.

2. Get comfortable

You may be on bed-rest for a while, so it is essential that you get comfortable.

- Get a u-shaped pillow to rest on if you can sit inclined.
- Put a chair in the shower if you are allowed shower privileges.
- Ensure your phone/iPad/laptop are in easy reach so you can keep connected with the outside world.
- Consider getting a tilt table that can be used in bed when eating meals and as a laptop table.
- If you are at home and going to be alone during the day, make sure someone has made lunch for you and left plenty of bottles of water within reach.
- Plan your entertainment for the day and make sure the TV remote, magazines and/or books are in easy reach.

3. Support networks

Seek support from friends and family

Don't be afraid to ask for help from your family or close network of friends. From cleaning the house, doing the school run, making the children's lunches, doing the laundry, helping out with the household accounts, making some meals to pop in the freezer, it all helps. Consider getting groceries delivered to your home when there is a support person with you who can help put away the groceries.

Online support

There are a myriad of online chatrooms and Facebook groups that offer support. If you find a great group of women going through bed-rest at the same time as you, with the same condition, it may be your key to feeling like you're not alone. However, be mindful of how much information you share about yourself online.

Tiny Sparks WA runs a Facebook support group for high-risk pregnancies. Search for 'Tiny Sparks WA High-Risk Pregnancy Support Group' and request to join.

Have a support person on stand-by

In case of an emergency visit to the doctors or hospital, have a list of family and friends you can call to take you, or care for your other children. You may want to have a hospital bag packed for emergency hospital admissions or at least have a list of items to help the support person pack for you.

Other support

If you don't have a support network, give us a call or speak to your midwife, doctor, or the social worker at your local hospital.



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Maxx and Indiana



Photo Credit: Lisa Nicole Imagery

Mum Lisa was on hospital bed-rest from 26 weeks due to no measurable length in her cervix. She soon after suffered Preterm Premature Rupture of Membranes (PPROM) and Indiana was born at 28 weeks. With her next pregnancy, Lisa was diagnosed with an extremely short cervix and funneling at 23 weeks 5 days gestation. She immediately had surgery to put in a transvaginal cerclage (TVG) and was given steroids with complete hospital bedrest in Trendelenburg position with a bedpan. Maxx was born 10 crucial days later at 25 weeks.

Alistair



Photo Credit: Blee Photography Perth

Mum Julie was on moderate to strict bed-rest at home from 12 weeks gestation when she had surgery to put in a preventative modified Shirodkar TVC. She had previously lost her baby girl Joséphine at 22 weeks due to cervical issues and PPRM. At 16 weeks she commenced progesterone pessaries with regular ultrasound monitoring. She suffered bleeding and an irritable uterus in the 2nd and 3rd trimester. She was given Nifedipine for the irritable uterus but was diagnosed with gestational diabetes at 28 weeks (managed by diet) and given steroids at 31 weeks. Alistair was born at 35 weeks weighing 2930g at King Edward Memorial Hospital. After 10days in SCN, he is now a happy healthy 1 year old.



4. Friends and family

Communicating your condition

Have a think about how much of your condition you want to share with your friends and family. Some people may be more understanding than others. Whilst some may be confronted by what you are going through and not keen to listen, others may appreciate you opening up and better understand your emotions if you explain to them what you are going through.

Be prepared for negativity

You will get all sorts of comments from people you come across, from "I wish I could spend a day in bed right now" to "Aren't you lucky you didn't have to sit through the school assembly tonight". Know that they are often saying these things because they don't know what else to say. Don't take it personally.

Visiting hours

If you have friends and family wanting to visit, pick your times when you think you might want company and schedule them in. There will be days when you are simply not up to visitors. Do not feel guilty about calling them and postponing your visit. They will understand. If you are up for a visit, get them to bring their own food and drinks (and some for you too!). There should be no expectation that you are entertaining.

5. Your other children

If you already have children that you care for, you will need to consider how you can best support them practically and emotionally. They may be too young to understand that your baby is at risk, but they will understand that for a little while Mummy won't be able to play with them like she used to or go to their school concerts etc.

To support them practically

- Arrange a schedule of school/daycare pickups and drop-offs among your friends and family.
- Get someone to make lunches for them (or if they are old enough - encourage them to do this for themselves).

To support them emotionally

- Have a stack of books to read to them.
- Give them lots of cuddles.
- Get them to do their homework in bed next to you.
- Ask them to help you by bringing you something small like a glass of water.

Keep in contact with their teachers/carers so that they are well supported at school/daycare and if you feel they are struggling with you not being able to be a 'normal mum', speak to the school counselor, daycare supervisor or your doctor.

6. Consider your finances

Bed-rest doesn't come without financial impact for mum's who are working.

- Discuss your options with your employer. Maybe you could telecommute, use accrued leave or start maternity leave.
- Consider how you might reduce your financial burden.
- Research what government assistance is available.



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Harley



Photo Credit: Amber Bates Photography

Mum Daniella was on hospital bed-rest from 27 weeks with pre-eclampsia. Harley was born at 33 weeks weighing 1810g. He had a few illnesses in his first few months of life and has asthma but is otherwise a healthy cheeky 2 year old!

Sam



Photo Credit: Amber Bates Photography

Mum Theresa's surprise pregnancy was carefully managed after delivering her firstborn, Stella, at 22 weeks 5 days gestation. She was put on progesterone suppositories once daily until birth and a cervical stitch was placed at 17 weeks. She was placed on bed-rest at home with fortnightly, weekly, and then twice weekly obstetric appointments. Sam was born by planned caesarian section at 36 weeks 6 days gestation, weighing 2865 grams. Photo above taken as a newborn. He is now a healthy 1 year old.



7. Emotions

Keep a diary

It's normal to feel anxious about your situation and there will be days when you need to vent! When you feel like no-one wants to listen, write it down.

Countdown

Counting down the days, weeks and months can give you a sense of purpose. Each milestone you meet, have a little celebration. Reaching viability, 26 weeks, 28 weeks etc.

Occupational therapy

Occupational Therapy can be either informal projects you've developed yourself, or sessions run by your local hospital. Consider:

- Reading.
- Sorting your digital photos.
- Knitting or crocheting a beautiful outfit for your baby.
- Shopping online (but be mindful of that credit card statement!)
- Downloading and watching that series on TV you've always meant to get around to seeing.

Do not be upset with yourself if you are unable to concentrate on any of these tasks. It is quite normal.

8. Be prepared for the future

Whatever your circumstance, learning about the different paths your pregnancy may lead to, can better prepare you for any outcome.

Neonatal Intensive Care Unit (NICU) & Special Care Nursery (SCN)

If you expect your baby to be born preterm, or sick, you may want to learn about the Neonatal Intensive Care Unit (NICU) and various equipment used. In Western Australia, the largest NICU (Level 3 Nursery) is at King Edward Memorial Hospital with a smaller unit at The Children's Hospital.

There are a number of Special Care Nurseries (also known as Level 2 nurseries) across the state that provide for babies who need some help to get home. You can find a list of hospitals providing Level 2 care on our website.

Please ask for our 'A guide to surviving the NICU/SCN' booklet.

Loss

If you have yet to reach viability, your thoughts may wander to the possibility of loss. You may want to consider whether you wish to hold your baby, name your baby or hold a funeral. SIDS and Kids provides professional counseling in this area. Heartfelt is an Australian based not for profit organization with volunteers who will take photographs of your stillborn, or enhance your own photos for free.

Coming off bed-rest

After weeks and possibly months lying on your back, you will need to be gentle with yourself. You may feel dizzy when you first get up and only be able to walk a short distance. If you spend too much time on your feet, your ankles may swell and bruise. Seek advice from your doctor and hospital physiotherapist for guidance on appropriate exercises/therapy. And remember to ask for help.



9. Useful Contact Details

Tiny Sparks WA

Phone - 9389 9040

Email - admin@tinysparkswa.org.au

Website - www.tinysparkswa.org.au

Twitter and Instagram - 'TinySparksWA'

Facebook Page - www.facebook.com/TinySparksWA

Facebook Forum - 'Tiny Sparks WA High-Risk Pregnancy Support Group'*

* Please note: Membership of this group is subject to approval by one of the Administrators, a Tiny Sparks WA volunteer. If you are not added by an existing member, you will receive a private message requesting you to provide background as to why you wish to join. Please check your 'Other Messages' folder and respond as soon as is practicable.

King Edward Memorial Hospital

Maternal Fetal Assessment Unit - 9340 2222

Maternal Fetal Medicine Service - 9340 2700

Psychological Medicine Consultation and Liaison Service - 9340 1521

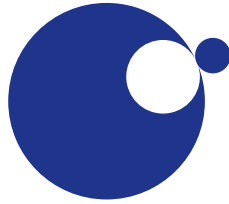
Other Maternity Hospitals in Western Australia

www.tinysparkswa.org.au/maternity-hospitals-in-wa

Women and Infants Research Foundation

The Western Australian Research Foundation Preterm Birth Prevention Initiative' - www.thewholeninemonths.com.au

Notes



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Igniting the fire within

Tiny Sparks WA is a not-for-profit charity run by local volunteer families, dedicated to improving the health and wellbeing of mothers enduring high-risk pregnancies, newborns requiring the neonatal intensive care unit (NICU) or special care nursery (SCN), and the communities supporting them in Western Australia.

Bed-rest can be an incredibly traumatic time for families. Worried about the health of your baby, you are also faced with day-to-day practicalities of not being able to carry on your normal life.

This guide has been developed to provide coping mechanisms to families, information on where to seek support, and hope for the future. It is written by parents who have experienced bed-rest. Parents who understand.