Motherhood Choices

A decision aid for women with Rheumatoid Arthritis

2nd edition

WESTERN SYDNEY UNIVERSITY

Arthritis & Osteoporosis NEW SOUTH WALES

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Contents

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Introduction

Is this booklet right for me?

This booklet is for you if:

- You are a woman with Rheumatoid Arthritis (RA); and
- You are thinking about whether or not to have a child or more children.

What is the purpose of this booklet?

This Decision Aid (DA) booklet is designed to help women with Rheumatoid Arthritis make an informed decision about pregnancy, breastfeeding and motherhood. It is meant to be used together with a Rheumatologist (or other health professional) and family.

Having a baby is normal but a big life event. Women who live with RA also have to manage their RA during and after pregnancy. This can be challenging. This DA booklet provides balanced information about the risks and benefits of different options before, during and after pregnancy. It is a starting point for information that women with RA need to know about RA, medicines, pregnancy, breastfeeding and motherhood.

It also provides a number of stories from women with RA who have either decided to have a child or decided against having children. In the back of this DA booklet there are some exercises to help work through some options, and things to consider when discussing options with health professionals and family.

"I look at my life this way. Diagnosed at age 28 with rheumatoid arthritis. Seven years later I have a debilitating severe illness that riddles almost every joint in my body. I live with pain, fatigue and limitation every day, as well as the impact of these things on every aspect of my (and my husband's) life – and will probably do so until a cure is found.

From where I stand, I have two choices. One, I lie down and let this illness stop me from achieving my goals in life. Allow it to rob me of even more than it already has. Or two, I stand tall and take control of my life by managing my health in a positive way alongside fighting to achieve everything that I desire – and deserve – in life."

Expectant mother

Rheumatoid Arthritis (RA)

What is RA?

RA is one of over 100 types of arthritis. It occurs when the body's immune system doesn't function as well as it should. The immune system is the body's defense system. Its job is to protect the body from foreign attack (bacteria, viruses and fungi) and prevent diseases from developing. In autoimmune conditions, the immune system cannot distinguish the body's own tissue from foreign substances, and as a result it mistakenly attacks its own tissue.

RA is an autoimmune condition in which the immune system attacks the healthy lining of the joints. All joints in the body are surrounded by a thin layer of cells called synovium that produces fluid to lubricate the joint tissue. In RA, the immune system is centered around the synovium causing chronic inflammation that doesn't resolve. The synovium then becomes thick and inflamed leading to unwanted tissue growth and release of chemicals (cytokines) into the joint and bloodstream. The tissue growth (pannus) and release of cytokines causes symptoms such as pain, stiffness, swelling and tenderness of the joints, as well as fatigue and tiredness. Joints and surrounding tissue often become damaged, leading to abnormal joint shape and alignment, resulting in deformities, as well as disability (Figure 1).

RA usually begins in the smaller joints, such as the hands and feet. For some people it can move to larger joints (e.g., shoulders, hips, knees, ankles and elbows) and other parts of the body that are not joints (e.g., skin, eyes, mouth). In more severe RA, the lungs, heart and blood may become affected. Although people can get RA at any age, it is commonly diagnosed between ages 30-50. However, the prevalence of RA is higher in older age groups.

Who gets RA?

RA is more common in women than men (3:1), and in women it starts at an earlier age. About 0.5 to 1% of the world's population on average will develop RA, although rates slightly differ between countries and regions.

Some 18% of women who have RA are diagnosed during their child-bearing years and may, at some point, face decisions about motherhood.

Rheumatoid Arthritis (RA)

What is RA's pattern?

RA is a chronic condition and its pattern varies between individuals:

- Some people (35%) may experience a complete remission (less or no symptoms) within the first two years after diagnosis.
- Some people (40%) may experience a series of intermittent flare-ups (worsening of symptoms), and periods of improvement during the course of the condition.
- Some people (20%) may experience a progressive deterioration of symptoms over time.

What is the prognosis?

Generally, the course of RA is not predictable. Although it is considered a serious condition, the prognosis has greatly improved with the development of a range of medicines that help to slow joint damage and the progress of the condition, especially if treated early. Overtime, a Rheumatologist may be able to identify individual RA patterns.

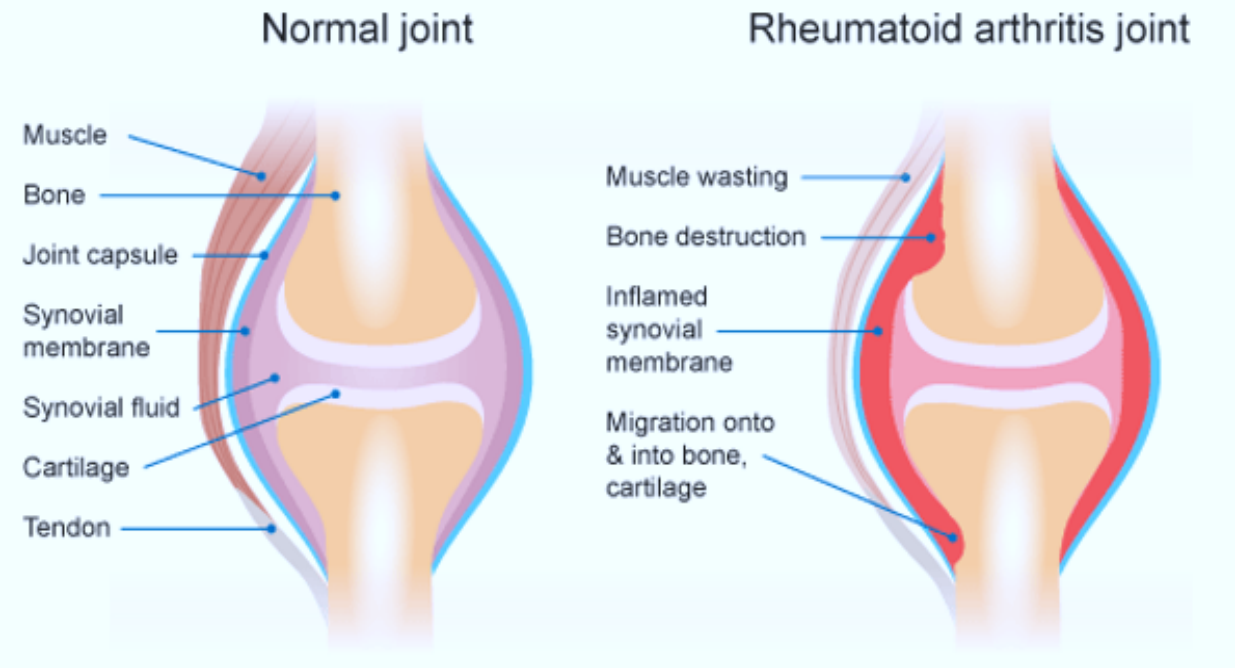


Figure 1 – Source: AIHW Musculoskeletal Fact Sheet: Rheumatoid Arthritis (2015)

Rheumatoid Arthritis (RA)

Many people with RA live normal lives and over time learn what works for them and how to best manage their condition. For some, however, RA can be hard to manage. It may impact on their daily activities, work and family decisions.

Pain and Fatigue

Pain is often the most troubling feature of RA. It can lead to fatigue, poor sleep and feeling depressed. Pain, however, can be well-managed with appropriate medicines and lifestyle self-care (i.e., rest, pacing of activities). Fatigue is a feeling of persistent low energy that is commonly experienced by people with RA. For some, fatigue is more troubling than pain or disability. It makes daily activities hard to do and rest may not help. However, when RA improves, fatigue may lessen.

Disability

People with RA are concerned about disability, because it may impact on their work and family life. But new medicines offer effective ways of managing RA. Most (90%) young people with RA (i.e., 25-44 years old) are able to care for themselves without help from others. Even many (75%) older people with RA (i.e., 65-79 years old) remain independent in self-care. Individual differences and flare-ups may increase disability at times. However, overall disability levels in RA are now better managed with improved treatments.

Life Expectancy

In some people, life expectancy may be reduced by RA's impact on the large organs such as the heart, lungs or kidneys. Some studies suggest that life expectancy may be reduced by 5 to 10 years if early treatment or prevention of complications is not undertaken. RA itself is not a direct cause of death. Life expectancy is influenced by many factors and can be improved by healthy lifestyle choices (e.g., exercise & diet; limiting alcohol intake; not smoking).

Employment/Financial

People with RA have the same legal right to work as people without RA. Some do so full-time (31%), others part-time (25%). Some may need to have job modifications (40%) or have extra time off (10%). However, up to 50% of people with RA find it necessary to stop work within 10-20 years of being diagnosed. For some, this may be earlier than they had planned. RA can also cause financial strain, as a significant proportion of household income may be needed for health care expenses.

Effects of RA

Relationships

Diagnosis of RA can change relationships. Some may be put under pressure, while others will become stronger. At times partners may become the care-givers, and the person with RA might find it hard to accept help.

Studies show that the majority of people with RA (about 65%) do not believe that RA impacts negatively on their relationship with their partner. However, the remaining 35% may experience some strain on their relationships, particularly when the condition is diagnosed while in an established relationship. Limited ability for activities, changes in the balance of the relationship, as well as emotional and financial changes can all place pressure on relationships.

Sexuality in relationships may also be affected by RA, with studies showing that a little over half of people with RA (56%) reporting that sexual intercourse is limited by their RA symptoms such as fatigue, pain and reduced joint function. However, these effects can be reduced if RA symptoms are well-managed.

Studies also show that strong supportive relationships, particularly where there is shared open communication between partners, can actually contribute to better physical and mental health, and may even improve inflammation in RA.

Having children is another challenge for relationships and RA. They bring extra duties and more expenses for both parents. Other family members may need to help sometimes. But having children also brings great joy and rewards and can further enrich relationships.

Effects of RA

> "Despite knowing that my partner could and would provide all the support that was needed, the thought of putting this sort of pressure on him was very difficult for me to consider. As it was there was a good chance that I would face major surgery and would need lots of care at some stage down the track and placing a child in this picture seemed very unfair for both."
>
> *Woman with RA decided not to have children*

Psychological

Many people with RA are able to manage their condition well. But there are times when living with RA can be a challenge. It may be hard to cope with pain, or difficult to work or take part in other activities. Some people with RA may experience depression or anxiety (13-20%) or have symptoms of those (40%). A General Practitioner (GP) can provide a referral to local mental health professionals to help cope with these challenges (see Resources section for further information).

> Having RA can impact on many areas of life including work, relationships, level of disability and psychological/emotional well-being. Most people with RA however, manage to cope effectively and lead full, normal lives.

Pregnancy and RA

Pregnancy

During pregnancy, a new life is created inside the woman's body. The unborn baby is referred to as a foetus. There are 3 stages of pregnancy, called trimesters. During each trimester the foetus goes through different stages of development and growth.

A usual pregnancy term generally lasts between 37 to 42 weeks. If a baby is born earlier than 37 weeks, it is considered premature, and may be at risk of health problems. Pregnancy impacts on a woman's hormone levels, leading to many physical and emotional changes, such as morning sickness, constipation, heartburn, frequent urination, and skin changes. Some pregnant women may also go through times of feeling tired and irritable, as well as frequent mood changes, especially in the early stages of pregnancy. During pregnancy it is recommended to maintain a healthy lifestyle including good nutrition, taking recommended supplements such as folic acid, maintain a healthy weight, and keep physically active.

It is recommended to avoid smoking, drinking alcohol, using drugs (including some prescription medicines), and being exposed to toxic chemicals, infectious diseases, x-rays and high temperature environments, as these may cause harm to the unborn baby.

How does RA affect Pregnancy?

The average age of women who have children is increasing to almost 30 and above. Therefore, there are many women who will make pregnancy decisions after the onset of RA.

RA and Fertility

RA does not seem to affect fertility. In general, women with RA have the same rates of fertility as women without RA. Women with RA tend to have fewer children than other women, but this is usually due to reasons other than fertility (i.e., pain, sexuality, or childbearing decisions). Also, it may take some time to fall pregnant, as the timing is different for every woman, with or without RA. Women with RA need to manage RA symptoms while trying to conceive. Any concerns about fertility are best discussed with an Obstetrician.

> "Coming off my arthritis medicines to safely conceive was an incredibly difficult challenge but one that was worth every sensation of pain and fatigue. In 2007, our son was born – I had proven to both myself and the arthritis world, that it is possible to have a child while also living with a debilitating and incurable illness."

Pregnancy and RA

RA and Pregnancy

For many women with RA their pregnancy, labour, birth time will be similar to that of any other woman. In general, RA does not change how the pregnancy progresses. But there is some research which suggests that women with RA may be slightly more at risk for:

- High blood pressure (hypertension);
- Preeclampsia (11.1% of women with RA vs. 7.8% of women without RA) - a medical condition that can occur in pregnancy and causes high blood pressure, protein in the urine and severe fluid retention; and
- Restricted growth of the baby (3.4% vs. 1.6%).

However, these complications are not common and most women with RA will have a healthy, normal pregnancy.

RA and Pregnancy Outcomes

The risk of serious, negative outcomes does not seem to be increased for women with RA or their babies. That is, RA does not increase the risk of miscarriage, still birth or birth defects, nor serious complications for the woman.

However, some research suggests that women with RA may be slightly more at risk for:

- Premature birth (26% of women with RA vs. 4.3% of women without RA);
- Earlier admission to hospital (15.6% vs. 11.2%);
- Caesarean birth (37.2% vs. 26.5%); and
- Longer hospital stays (3.1 days vs. 2.5 days on average).

Pregnancy and RA

Although women with RA are more likely to experience the above complications, for the most part they will not encounter long-term negative outcomes. Most women with RA will have an uncomplicated labour and birth. Local hospitals and health services offer prenatal classes, and there is a lot of written information about pregnancy, labour and delivery choices. Any further needs or concerns should be discussed with a specialist.

Does RA run in families?

RA is linked to a family history of the condition, and about 10% of people with RA have a first degree relative (i.e., parent/sibling) with RA. Specific genes have been identified as risk factors for development of RA. However not everyone who carries those genes will develop RA and not everyone who has RA carries those genes. This suggests that there are other factors involved in the development of RA.

For those people who have a genetic susceptibility to RA, environmental factors, especially smoking, may be involved in triggering onset of the condition. In addition, infections, viruses and possible immune system abnormalities are also considered possible risk factors. Overall, RA is the result of a combination of both genetic and environmental factors, although it is still unclear exactly how and to what degree they contribute.

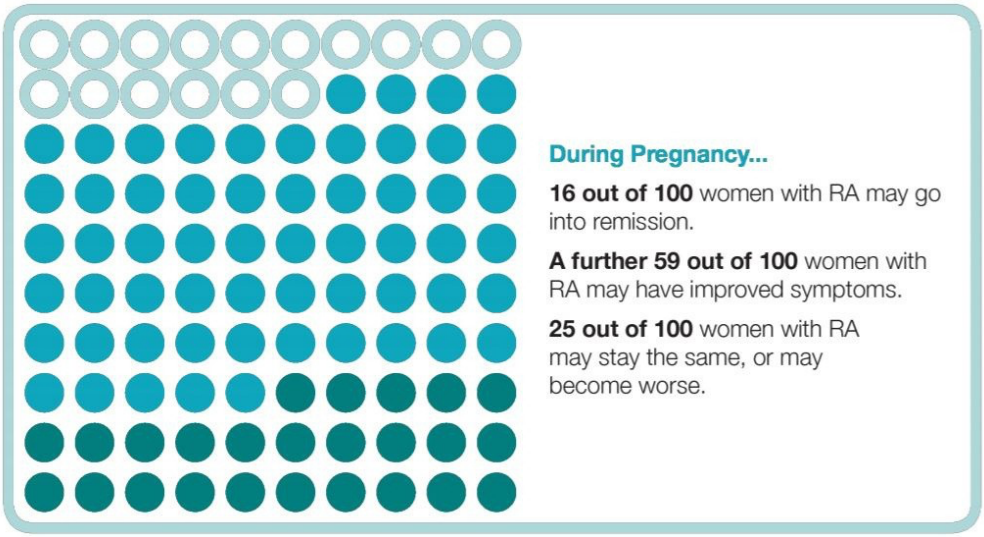
How does Pregnancy affect RA?

For most women (75%), their RA will get better during pregnancy. This is because pregnancy causes changes in hormones, which in turn affect the immune system. These change scan help RA symptoms. Joint pain, morning stiffness and fatigue may improve. Usually these changes are noticed during the first trimester and may continue throughout the pregnancy.

For a smaller number of women (16%), their RA may even go into remission during pregnancy. For some women (25%), their RA will stay the same or may get worse. After the baby is born, the positive effects of pregnancy slowly fade. This means that most women experience a flare up of RA within 3-4 months of childbirth.

> "I was one of the unlucky ones when they said my RA could go in to remission with pregnancy, but I would not have it any other way, my children are the best! I think no matter how bad you feel if you have the support of family and friends you can manage."
>
> *Mother of two*

Pregnancy and RA



Long-Term Affects of Pregnancy on RA

In the short term, some pregnant women with RA may feel more pressure in their joints because of weight gain. In the long-term, pregnancy does not seem to impact on the course of RA. Joint damage and disability are not made worse by pregnancy.

"During the time of considering pregnancy I talked a lot with a wonderful colleague about the decision-making process about the need to grieve should we decide against having a baby and about my partner's needs as a potential father. These conversations were very helpful and allowed me to reflect and appreciate the driving forces for and against having a baby. "

Woman with RA decided not to have children

In summary...

Many women will make pregnancy decisions after diagnosis is of RA as it is commonly diagnosed during child bearing years. RA does not seem to affect fertility, nor does it change how a pregnancy progresses. Although women with RA are slightly more at risk for some complications during pregnancy and delivery, these are generally not serious. Most women with RA will have improved RA symptoms during pregnancy, but these effects usually fade soon after the baby is born. Relapse in the postnatal period is common. Overall, women with RA will have a healthy, normal pregnancy.

RA Medicines and Pregnancy

Women with RA may be concerned about the effect of their medicines on conception, pregnancy, breastfeeding and the health of the baby. Treatment of RA often involves a mix of two or more medicines. It is helpful to know how these medicines work, and how safe they are if taken before, during and after pregnancy.

Where to Get Information about RA Medicines

A Rheumatologist is able to determine the best medicine treatment before, during and after pregnancy. It is very important to talk with a Rheumatologist about the possible side-effects of medicines. They have the most up to date and relevant information and know how to apply it to individual cases.

There is also written information available that can help. The first step is to read the labels of all the medicines used for RA and any other conditions. These labels may include warnings and instructions about pregnancy and breastfeeding. If not, please consult the Consumer Medicine Information (CMI).

CMI provides details of all prescription and some over-the-counter medicines. CMI documents are available from Doctors, Pharmacists and online (www.medicines.org.au). [See Resource list at the end of this booklet for international medicines information resources].

Questions to Ask a Rheumatologist

A Rheumatologist is the most important person to talk to about any medicine concerns. If you have RA and are thinking about having a child, it is important to speak to a Rheumatologist well before trying to get pregnant.

Some of the things to discuss with a Rheumatologist may include:

- The impact of stopping current medicines* while trying to get pregnant.
- The amount of time that should be allowed for a "wash-out" (the time needed for medicines to leave the body) before conceiving.
- What options there are for managing RA symptoms while trying to conceive. The risks and benefits of medicines before and during pregnancy.
- The risks and benefits of medicines while breastfeeding.
- Any other related concerns.

* All the medicines you may be taking: RA and other conditions, prescribed and over-the counter, and complementary medicines.

RA Medicines and Pregnancy

"Being newly diagnosed with RA and Sjogren's Syndrome, I was very anxious, worried and depressed about my diagnosis. My main focus at that stage was to come to terms with the disease, adjust to the impact it would have on my life and learn as much as I could about what treatments were available. As soon as I was able to get an appointment with my Rheumatologist, I discussed the prospect of becoming pregnant and as a result, he was able to tailor my medications to suit my needs."

Expectant mother

Types of RA Medicines and Their Functions

Medicines used to treat RA may be grouped into six types which are used alone or in combination:

- **Analgesics** (Pain Medicine; e.g., Paracetamol).
- **Non-steroidal anti-inflammatory drugs (NSAIDs**) (e.g., Ibuprofen, Nurofen, Naproxen,Cox 2 Inhibitors such as Celecoxib, Meloxicam, Etoricoxib). These are used to reduce pain and inflammation and are available over the counter or by prescription.

RA Medicines and Pregnancy

- **Disease modifying antirheumatic drugs (DMARDs)** (e.g., Hydroxychloroquine, Methotrexate, Sulphasalazine, Leflunomide). These are used to reduce pain and swelling and slow down the progression of RA and are only available by prescription.
- **Oral corticosteroids** (e.g., Prednisolone, Prednisone). These are used to reduce pain and swelling and are usually prescribed alongside NSAIDs and DMARDs and are available by prescription.
- **Biologic** agents are a type of DMARD, derived from living material, mainly used to treat severe RA and are usually prescribed by a Rheumatologist soon after diagnosis. With research and development there are now newer agents available with greater choice, flexibility and options for the treating Rheumatologist. These include TNF inhibitors (Etanercept, Infliximab, Adalimumab, Certolizumab and Golimumab), B cell inhibitors (Rituximab), and T cell inhibitors (Abatacept). Although not strictly biologic agents, new drugs called JAK kinase inhibitors (Tofacitinib, Baricitinib, Upadacitinib) have been approved for use in moderate to severe rheumatoid arthritis.
- **Complementary/Natural remedies** (e.g., fish oil, folic acid). These are available over the counter.

RA Medicines

The following pages give information about some of the more commonly used medicines in RA. But this is not a complete list of ALL RA medicines. More information is available from the Resources listed in the back of this booklet. It is important to understand that any information given here about the use of medicines before and during pregnancy and breastfeeding is limited. This is because –

1. The information may be based on:
   a) Experimental research, mostly done with animals; or
   b) Clinical observations, rather than controlled studies; or
   c) A relatively small number of studies done with women who have RA; and
   d) Risk classification systems that vary across countries.
2. Information is always changing as more research is done.

Information about medicines is very complex and it is essential to consult with a Rheumatologist about any aspect of medicines issues.

RA Medicines and Pregnancy

DISCLAIMER: The information in this booklet is intended as a guide only and a starting point for conversation with a Rheumatologist, other health professionals, family and significant others. No decision should be made based on this information alone. A Rheumatologist should be seen before making any changes to treatment medicines.

Analgesics (Pain Medicine)

Analgesics are used for pain relief and come in various dosages.

Paracetamol:

- **Paracetamol** (e.g., Panadol®) is considered safe for use in pregnancy, taken at recommended doses. Although it crosses the placenta and is secreted in breast milk, there is no evidence to suggest harmful effects to the baby. Therefore, its use in pregnancy and during breastfeeding is generally not discouraged.
- Slow release **paracetamol** (e.g., PanadolOsteo®) is also considered safe during pregnancy in recommended doses.
- **Paracetamol** combined with codeine (e.g., Panadeine®) is considered safe during pregnancy if advised by a Rheumatologist. It is not recommended while breastfeeding because codeine is excreted into breast milk and may cause harm to the baby.
- All narcotics at high doses should be avoided near term because of the risk of neonatal depression and/or withdrawal.
- Overall, while **paracetamol** can be used safely occasionally in pregnancy, regular **paracetamol** use during pregnancy or breastfeeding should be discussed with a doctor.

Aspirin®:

- **Aspirin** in high doses and long-term use is considered **potentially harmful** in pregnancy. It should be avoided altogether in the third trimester.
- During conception and the first two trimesters of pregnancy, **Aspirin** may be safe in low doses, and helpful in preventing high blood pressure and preeclampsia.

- **Aspirin** is associated with increased risk of prolonged gestation, long labour, increased blood loss and infant bleeding.
- **Aspirin** should be avoided in the third trimester due to risk for heart defects in the baby. **Aspirin** should be avoided while breastfeeding as it passes into the breast milk and increases the risk of infant bleeding.

Non-Steroidal Anti-Inflammatory Drugs (NSAIDs)

E.g., Ibuprofen, Naproxen, Cox 2 Inhibitors, Meloxicam (Mobic®), Celecoxib (Celebrex®), Etoricoxib (Arcoxia®)

NSAIDs:

- **NSAIDs** are considered **potentially harmful** during pregnancy and should be avoided in the first and third trimester.
- Some research suggests that **NSAIDs** may impair fertility, but this effect may be reversible when **NSAIDs** are stopped.
- **NSAIDs** should be avoided throughout pregnancy, especially the first and last trimesters. **NSAIDS** cross the placenta and may increase the risk of miscarriage.
- If taken during the third trimester, there is increased risk to the infant, including bleeding, hypertension, impairment of renal function and heart defects.

Disease Modifying Antirheumatic Drugs (DMARDs)

E.g., Hydroxychloroquine, Methotrexate, Sulfasalazine, Leflunomide

DMARDs:

- **DMARDs** are used to reduce the progress of RA. **DMARDs** are generally considered **harmful** or **potentially harmful** during pregnancy, however there is increasing research to suggest that some medications within this sub-category may be safe for use during pregnancy and breastfeeding.
- The specific effects of individual **DMARDs** are discussed below.

Hydroxychloroquine (HCQ) (e.g., Plaquenil®):

- **HCQ** is a slow releasing medicine, which means that it accumulates in the body slowly, and remains in the body longer.
- Recent research and long term follow up[1] have found that **HCQ** is not associated with any increased risk of harmful effects to the infant. As a result, **HCQ** has become more widely prescribed during pregnancy and breastfeeding in recent years.

RA Medicines and Pregnancy

Methotrexate (MTX) (e.g., Methoblastin®):

- **MTX** is frequently used to treat RA, alone or in combination with other DMARDs. **Methotrexate** is **contraindicated** in pregnancy.
- In pregnancy, **MTX** is considered harmful and is contraindicated when trying to become pregnant, during pregnancy or breastfeeding.
- **MTX** should be discontinued at least 3 to 4 months prior to conception and must be stoppedas soon as an unplanned pregnancy is discovered.
- **MTX** crosses the placenta and is linked to high rates of miscarriage. It is harmful to foetal development.
- **MTX** is also excreted into the breast milk and is not recommended while breastfeeding.

Sulfasalazine (e.g., Salazopyrin®):

- **Sulfasalzine** is classified as **safe** for use in pregnancy.
- Although **Sulfasalazine** crosses the placenta and may carry a risk to the foetus, research does not clearly suggest harm or assure safety - although the risk to the infant is believed to be low.
- **Sulfasalazine** could cause folic acid deficiency that may lead to neural defects if not controlled with folic acid supplements.
- A small amount of **Sulfasalazine** excretes into the breastmilk. However, it can be used in breastfeeding. In males taking **Sulfasalazine** it reduced the sperm count and can affect fertility[2].

Leflunomide (e.g., Arava®):

- **Leflunomide** is classified as **harmful** and not recommended for use during the conception period, pregnancy and breastfeeding.
- **Leflunomide** remains in the body for at least 14 days and its traces can persist for up to 2 years. It is therefore recommended to cease 2 years prior to conception.
- Women on **Leflunomide** are encouraged to use a reliable contraception method and not become pregnant while taking this medication.
- To prevent exposure to the foetus, **Leflunomide** has to be stopped many months before conception. If you have been on **Leflunomide** and wish to conceive, and it is within 1-2 years since stopping, you will need to consult your rheumatologist on what steps to follow. This may involve a washout with cholestyramine or activated charcoal and have two blood levels checked 14 days apart.

- Some research links **Leflunomide** to high rates of miscarriage, risk for premature birth and low birthweight.
- Due to potential harm to the infant, it is not recommended during breastfeeding.

Cyclosporine (e.g., Sandimmunn®, Neoral®):

- **Cyclosporine** is classified as **potentially harmful.**
- Based on limited research and current guidelines, **Cyclosporine** can be used in pregnancy at lowest effective doses and with careful monitoring of maternal blood pressure, renal function and blood glucose[1].
- There is potential for increased risk to the infant and mother, such as poor foetal growth, premature birth, and maternal hypertension (high blood pressure).
- Paternal exposure to **Cyclosporine** is considered safe.
- It can be used while breastfeeding. Australian clinical guidelines state that breastfeeding should not be discouraged when **Cyclosporine** is taken at low doses[1].

Azathioprine (e.g., Imuran®):

- **Azathioprine** can be continued during pregnancy and breastfeeding if needed. Several reports show no increase in congenital anomalies in disease matched controls[1].

Oral Corticosteroids

E.g., Prednisone (Panafcort®), Prednisolone (Panafcortelone®)

Corticosteroids:

- **Corticosteriods** in short-term use and low dose (i.e., less than 10mg daily) are classified as safe during pregnancy and breastfeeding.
- Most studies do not show evidence of foetal defects.
- **Corticosteroids** cross the placenta, but only appear to increase risk if used long-term or in large doses.
- Risks for the woman include high blood pressure or preeclampsia and pregnancy induced diabetes.
- Risks for the foetus include oral cleft defects, premature birth and low birth weight). **Corticosteroids** are secreted in the breast milk in small amounts.
- **Corticosteroids** are considered safe during breastfeeding, but only on the advice of a Rheumatologist when the benefits outweigh the risks.

RA Medicines and Pregnancy

Biologic Medicines

E.g., Infliximab (Remicade®), Etanercept (Enbrel®), Adalimumab (Humira®), Certolizumab (Cimzia®), Golimumab (Simponi, Simponi Aria®), Abatacept (Orencia®), Rituximab (Rituxan®), Tocilizumab (Actemra®), Tofacitinib (Xeljanz®) – As biosimilars come into the market, the tradenames of these medicines may be different.

- Biologic medicines are a type of DMARD that are better at controlling RA progression because they target specific parts of the immune system that fuel inflammation.
- They are produced by genetic engineering from living cells, as opposed to most other medicines which are natural or synthesized chemical compounds.
- There is now a new class of medications that are targeted synthetic compounds that have specificity for the immune system. They are termed Janus kinase (JAK) inhibitors (**Tofacitanib, Baricitinib, Upadacitinib**).

Tumour necrosis factor inhibitors (TNFi) (e.g., Etanercept (Enbrel®), Infliximab (Remicade®), Adalimumab (Humira®) Certolizumab pegol (Cimzia®) and Golimumab (Simponi®):

- **TNFi** inhibit TNF, which is a central key factor driving inflammation.
- **TNFi** biologic agents cross the placenta in small quantities during the first and second trimesters, but in larger amounts during the third trimester. The only exception is **Certolizumab** which is not actively transported across the placenta or secreted in breast milk, therefore may be recommended in pregnancy and breastfeeding.
- Current evidence supports continuing **Infliximab** up to 16 weeks and **Adalimumab** (Humira) and **Etanercept** (Enbrel) up to 32 weeks and then stopping[1].
- **Etanercept** (Enbrel) may be continued throughout pregnancy if indicated[1,2].
- There is currently insufficient data in relation to **Golimumab** in pregnancy, but Australian recommendations state it is unlikely to be harmful in the first trimester[1].

Interleukin-6 (IL-6) inhibitors (e.g., Tocilizumab (Actemra®):

- **IL-6 inhibitors** act to reduce IL-6 levels which is another factor driving inflammation and immune activation in RA.
- Not enough is known about **IL-6 inhibitors** in pregnancy. In the absence of sufficient data, it is recommended that IL-6 inhibitors be stopped 3 months before conception.
- Breastfeeding is likely to be safe based on limited research.

RA Medicines and Pregnancy

Monoclonal antibodies against B-cells (e.g., Rituximab):

- Current recommendations are to cease 6-12 months prior to conception and avoid during pregnancy[1,2].
- If unplanned pregnancy occurs, contact high risk birth units to discuss management and monitoring.
- There is insufficient data in relation to paternal exposure or use in breastfeeding.

Monoclonal antibodies against T-cell co-accessory molecules (e.g., Abatacept (Orencia ®):

- There is currently insufficient data to recommend in pregnancy, however unintentional exposure during the first trimester is unlikely to be harmful[1,2].
- There is insufficient data to support use in breastfeeding or about the impact of paternal exposure.

Janus kinase inhibitors or JAK inhibitors (e.g., Tofacitinib (Xeljanz®), Baricitinib (Olumiant®), Upadacitinib (Rinvoq®):

- Should be avoided in pregnancy and breastfeeding.
- Should be stopped three months before planned conception.

Complementary/Natural Therapies

Some people use complementary/natural therapies in addition to their prescribed medicines. It is important to let the treating Rheumatologist know if such treatments are used as they may have side-effects and interact with prescribed medicines. While there are many such treatments that may be used, one that is commonly used by people with RA is **Folic Acid.**

Folic Acid:

- **Folic Acid** is a supplement for folate, a B-vitamin that occurs naturally in food. **Folic Acid** is not only considered safe but essential for use in pregnancy.
- It is often prescribed in RA alongside Methotrexate (MTX) to prevent folic acid deficiency and minor side-effects that may result from MTX usage.
- It is also considered beneficial to all women prior to conception and during pregnancy, because it helps to produce and maintain new cells, and protect the baby against brain and spinal cord defects.
- More detailed information about various complementary remedies is available from: https://www.versusarthritis.org/about-arthritis/conditions/rheumatoid-arthritis/

RA Medicines and Pregnancy

In summary...

Many medicines are used in the treatment of RA. These medicines vary in their impact on conception, pregnancy, breastfeeding and infant development. It is essential to consult a Rheumatologist well in advance of conceiving as some medicines may need tobe stopped early, so not to adversely effect conception and foetal development. Women may differ in their RA pattern, their medicine needs, and pregnancy and breastfeeding experiences. Therefore, it is important to consider one's own needs in consultation with a Rheumatologist and family/significant others.

PLEASE NOTE: Patients should not self-medicate or change medication and dose without prior consultation with a Rheumatologist.

Your Notes:

1. Australian Rheumatology Association (2018). Prescribing medications for rheumatic diseases in pregnancy. Accessed online: https://rheumatology.org.au/gps/documents/ARAPregnancyPrescribingnotes151018final 000.pdf

2. Flint, J., Panchal, S., Hurrell, A., van de Venne, M., Gayed, M., Schreiber, K., Arthanari, S., Cunningham, J., Flanders, L., Moore, L., Crossley, A., Purushotham, N., Desai, A., Piper, M., Nisar, M., Khamashta, M., Williams, D., Gordon, C., & Giles, I. (2016). BSR and BHPR guideline on prescribing drugs in pregnancy and breastfeeding—Part I: standard and biologic disease modifying anti-rheumatic drugs and corticosteroids: Table 1. *Rheumatology, 55*(9), 1693–1697. https://doi.org/10.1093/rheumatology/kev4

The Postnatal Period

Bringing home a baby from the hospital is both a joyful and a daunting time for anywoman, especially if it is a first child. All new mothers wonder at times how they will cope. They may worry about feeding, getting into a routine, having enough sleep, while still managing a household and looking after their other children.

Women with RA may also have added concerns about how to manage their medicines and RA flare ups while looking after their baby. For most women with RA, their improved symptoms will not last very long after the baby is born. For a majority of women (90%), a flare up of symptoms will occur within 3-4 months of birth. However, a treating Rheumatologist will be able to prescribe an appropriate treatment.

How does Breastfeeding impact on RA?

Given that the majority of women with RA will have a flare up of symptoms within the first 3-4 months of birth, they may need to resume taking their medicines. As a result, they will have to consider their baby feeding choices. Generally, decisions about feeding method are influenced by health, lifestyle and comfort levels.

For women with RA, decisions may be also influenced by the need to negotiate caring for their baby's needs while also caring for their own health. Some women with RA may decide to hold off on taking their medicines while they are breastfeeding. It is important to consider that staying off medicines for an extended period of time may increase damage to the joints. This will impact on levels of pain and disability, and in turn ability to physically care for the baby (such as lifting, holding, bathing, changing). Therefore, women with RA are challenged with the balance they have to find between their own and their baby's needs.

The World Health Organisation (WHO) recommends breastfeeding for at least 6 months, and up to 2 years. Breastfeeding provides nutrients for growth and development and helps build up the baby's immune system. However, some women with RA may not be able to breastfeed or breastfeed for as long as they would prefer, because some medicines used to treat RA may secrete into breast milk and be potentially harmful to the baby.

Some research suggests that breastfeeding may worsen a flare up of RA symptoms particularly for women with severe RA. Bottle feeding provides a good alternative to breastfeeding and many women choose to bottle feed for various reasons. For women with RA, bottle feeding allows them to resume their RA treatment fully, maintain good health and lessen disability.

The Postnatal Period

Infant formulas have been developed based on many years of careful clinical research and continuing improvements and contain the required nutrients that are as close to breast milk as possible. Like breastfed babies, infants who are formula-fed are able to sustain a rapid rate of growth and development without stress on their developing organs. Formula feeding also has practical advantages of allowing their partners and/or other family members the opportunity to help with feeding time.

Therefore, women with RA have options that they can consider in relation to their individual needs. It is important to remember that either method of feeding allows parents to care for and bond with the baby.

Postnatal Depression

Having a baby is a big, life changing event and many women may find it hard at first to adjust to motherhood. Most new mothers may feel down or sad at times, referred to as “baby blues”. The 'blues' are usually temporary and will pass with time.

For some women, this feeling of sadness can continue and may get worse over time and can develop into postnatal depression. Postnatal depression is different to 'baby blues' and usually requires treatment by a mental health professional (i.e., a psychiatrist or psychologist).

Postnatal depression affects about 16% of women in Australia and can develop within weeks or months of giving birth. It can be caused by a range of things such as:

- Previous depression/anxiety; and
- Issues relating to the pregnancy, birth experience or parenting such as:
    - Physical changes (labour and birth, hormonal changes, sleep deprivation exhaustion);
    - Emotional changes (adapting to parenthood, problems with the newborn baby’s health/sleeping/feeding etc.); and
    - Social changes (social expectations of being a mother, loss of contact with friends/workmates, financial pressures).

These changes may lead to feelings of sadness, loss of interest and pleasure in activities, poor sleep and tiredness, changes to appetite, negative thoughts and feelings, and feeling unable to cope.

Given that there is a higher rate of people with RA who have depression, the challenges of managing RA, pregnancy and a young family may place women with RA at a greater risk for postnatal depression.

The Postnatal Period

Postnatal depression can be treated successfully. It is important to recognise that women with RA may be faced with greater difficulties in the first few months of birth. It helps to have a good support network to call on when needed.

A General Practitioner (GP) can provide a referral to local mental health professionals to help cope with postnatal depression (see Resources section for further information).

Your Notes:

Parenting with RA

Being a parent involves both physical and emotional care and can be challenging and demanding but also very rewarding. Having RA does bring added challenges. It means being able to balance mothering tasks with managing energy and flare-ups. Trying to keep this balance may at times be stressful for everyone in the family.

> "I believe that becoming a parent is a privilege – but it is also the most natural thing a person can do. My son and the baby that grows within me are my shining light. They are the little beings that get me out of bed in the morning when I am so stiff and sore andriddled with pain that I don't know if I can face the day. They are what make me want to be the best person I can be despite arthritis - and the best mother I can be. One of the many gifts I will give them Is the strength and determination to achieve anything they desire in life – regardless of what challenges are presented in their path. They will hopefully look to their mother throughout their lives and feel proud of not only the sacrifices she made to give them lite, but of her strength to 'live' her life and flourish in the face of adversity."
>
> *Mother of one and expectant mother*

Practical Considerations

Women with RA often worry about how they will be able to physically care for their baby. Physical tasks such as lifting, holding, feeding, bathing, changing nappies and dressing may be difficult to do at times. When the child is older, it may be sometimes hard to join in play and activities with them.

However, children tend to accept what their parents can or cannot do and enjoy whatever quality time their parents can give them. It is important to do as much as is possible within RA limitations and let family members or friends help out when needed.

A local organisation office is also able to help with information and support for managing parenting tasks.

Parenting with RA

"While we had discussed issues surrounding the care of a child in our decision-making process, our focus had been on the preconception period and the actual pregnancy. In hindsight for me, the post birth period has actually given us the most problems ... especially ... early on as a new baby has no understanding that it may take you a few minutes to get out of bed. All they know is that they have a need that they want dealt with immediately. Life is getting easier as she gets older though. She is less reliant on me for many things now and has also learnt to adjust to my abilities, such as climbing uponto the lounge when she needs a cuddle rather than me lifting her up all the time. Even with wonderful help from my husband, there are times when you are the only one available, or the only one who can provide what is needed. That said, many of the early issues I experienced were not dissimilar to other first-time mums who didn't have RA andI just have to look into that little face to know that any issues we have faced along the way are more than worth it."

Mother of one

Psychological and Social Considerations

Expectations of Self

Many women will have their own personal expectations of being a 'good mother and parent' which can be hard to live up to all the time. Women may go through times when they feel frustrated, guilty, distressed or inadequate.

Women with RA are often concerned about their own physical limitations and if they can meet their child's needs. They are also often concerned about their child inheriting RA. It is important to know where to look for information and support that is available and seek help when needed (see Resources section).

It is also important to know that all new mothers struggle with some of the same concerns.

Social Network

Family and Friends

It is important to seek and accept support from a partner, a family, friends and relevant services (see Resources section). A support network is needed by all mothers, especially those with RA.

Parenting with RA

However, women with RA sometimes say that they don't like to ask for help from others. This is because they may feel guilty if they are unable to be the mothers they think they should be. It is important to set realistic expectations and to remember that the whole family benefits when a mother is helped and supported.

> "Never feel ashamed to ask for help when the pain is unbearable. Always know your limits! Rest if you need to when it is bad, the chores never go away, and you will always catch up. If you think about it there are always ways around it to enjoy your children evenwhen the times are tough with the disease."
>
> *Mother of two*

Health Care Team

There are many resources available if the external social support is needed. Some of these are listed in the Resource section.

There are also many health professionals who can provide advice and support for parents with RA. These may include:

- General Practitioner (to oversee overall care);
- Rheumatologist (to manage RA and medicine);
- Obstetrician (to manage pregnancy);
- Midwife (to assist with pregnancy, labour, birth and the postnatal period);
- Early Childcare Nurse (to assist mother and baby in the postnatal period);
- Physiotherapist (for pain and disability management);
- Occupational Therapist (for daily living management skills);
- Clinical Psychologist/Psychiatrist (to assist with coping and distress);

In addition, local community health centres may offer various types of assistance, as do other services (see Resources section).

Parenting with RA

> "Although my pregnancy isn't progressing as pain free and simple as I'd like it to have been, I would still choose to go ahead with it. I like to think that the pain won't be forever, there are ways to manage the pain and there are many ways to get the support I need to get through it. I always communicate with my partner, so he knows what I'm going through and can help out when I need extra assistance. My friends, family and work colleagues are also sympathetic to my needs and I am able to gain strength and support from them too. Being a member of my local Arthritis organisation has also been beneficial to me as I've been able to meet other people with RA and learn more about the disease and management plus gain much needed support from people who know what I'm going through."
>
> *Expectant mother*

How will my children be affected?

Research has shown that children who grow up with parents who have physical conditions maybe both positively and negatively affected by their parent's condition.

On the one hand, these children tend to have a strong sense of family responsibility as they may sometimes have to take on a care-giving role within the family. This may help them become more empathetic and caring in the long term.

When children are knowledgeable about the condition, they can better understand why their parent may not be able to do certain activities sometimes and learn how to seek assistance or support from other family members and friends if necessary. For mothers with RA, children can be great motivators for remaining active and engaged, even when not feeling up to it. This may help in managing RA as well as overall well-being.

On the other hand, some children feel overwhelmed if they have to take on a care-giving role. Some children may go through periods where they feel sad or worried about their parent or feel angry or frustrated that their own every day activities might be restricted as a result of their parent's condition. Also, a child's emotional state may be influenced by the parents' emotional state, and the family overall adjustment to the chronic condition.

Having a parent with RA may add to the stressors and challenges of growing up. However, with strong family and social support, children can learn how to cope effectively with life challenges.

Parenting with RA

"Being slow and fumble-fingered [myself] wasn't such a bad thing either; [my daughter] could tie her own dressing-gown cord at 3½ and tie my shoe laces at 5 when I had jointsreplaced in my fingers."

Mother of one

My Notes

This Decision Aid information booklet may be used as a starting point, for you to ask the 'right' questions to help you make an informed decision. At this point you may have questions or comments that you'd like to write down and think about and/or seek further information on.

Women's Stories

Fiona: Decided not to have children

It seems that the question of how RA might affect my ability to have children was possibly on my mind within moments of being diagnosed at the age of 16. I was told by the doctors that the future was pretty unclear. Despite this I was pretty much in denial as to the gravity of the situation and spent a lot of time in early years refusing proper treatment.

The decision to have a baby was not really something that I dwelled on all that much. It was definitely put in the "too hard basket". My somewhat dormant maternal instinct, passion to change the world, commitment to my career and my hobbies and interests were all influencing factors.

It wasn't until I met my current partner in my late twenties, who really forced me to face the "ticking biological clock" question that I realized it was now or never, and this question continued to come up during my thirties. My partner recognised that while children would be a wonderful opportunity and that he was more than capable of being a parent, there was also an honest appreciation of the reality of the situation. For me I was anxious about the whole thing - from start to finish. Research and picking the brains of my Rheumatologist had provided me with information that I needed to consider about changing my medications, risks to the baby because of my age and medical complications, and the likely relapse of RA after the baby was born.

It seemed the image of being in a wheelchair was one that etched itself in indelible ink. I also couldn't help but to consider how the RA was going to impact on my ability to provide physical and emotional support to our child. How was it going to be for this child to have a parent with a chronic debilitating illness, along with all the issues involving mental health, family and financial stress etc?

> "Never feel ashamed to ask for help when the pain is unbearable. Always know your limits! Rest if you need to when it is bad, the chores never go away, and you will always catch up. If you think about it there are always ways around it to enjoy your children evenwhen the times are tough with the disease."

The cliché "There's more to life than ... ", might be unhelpful to those considering pregnancy but the reality is, there really is a lot that life can offer, without a child. Recognizing how incredibly lucky I have been to have such a wonderful partner has been critically important. Of course, there is and will be times we wonder how life might have been with a child around. How the combination of our genes might have looked? What their interests and strengths might have been? These thoughts however definitely don't linger.

Women's Stories

Jane: Decided to only have one child

I was diagnosed with RA when I was in my twenties – in a serious relationship but not quite at the "getting married and having children" point. Even though the condition started gradually with little change to my appearance or abilities, my partner and I knew there were serious implications to consider regarding having children.

We did some research into the probability of passing on the condition, the need to stop certain medications that were considered likely to cause birth defects, the probable flare-up soon after the birth, as well as managing a small baby, and later an older child. I have good family support and my partner is the best possible person I could imagine sharing my life with my special needs – he can cope with anything and does not fuss.

With good medical advice and support from health professionals in occupational therapy, maternal and child health and my local Arthritis organisation, we decided four years later to try for a child and see how we went. I did feel like a science experiment for a while, with the Rheumatologist advising certain medication-free time frames before conception and the Obstetrician/Gynecologist recommending surest ways to conceive on the first try. But it was successful, and we became the proud parents of a beautiful daughter.

During my pregnancy, I felt more well and energetic than I had for years. But within days of delivery my sore joints returned; then worse and in more places than before. Because no-one could say for sure what I would expect, I wanted to try to breastfeed at least for a while, so of course that meant no meds still. Hubby took a month's long service leave when I came homefrom hospital and we managed between us. When he went back to work I struggled to get through the day, but family members would visit me to help a couple of times a week.

When my daughter was eight weeks I stopped breastfeeding in order to go back on my meds. The Obstetrician/Gynecologist had primed me with trial packs of formula and the advice to feed the baby breast milk from a bottle once a day, so the dramatic change wasn't so terrible after all. She certainly didn't seem to suffer. In fact, she learned very quickly to help. That doesn't mean she always did it, but that's another story. PS. We stopped at one. Been there, done that.

> "Going back on treatment took a while to be effective; it was just on six months before I felt I was coping OK again, but things got better, and my daughter developed and learnedand played and did all the things babies should."

Women's Stories

Kate: Decided to have more than one child

I was diagnosed with RA in my late twenties. It was picked up relatively early and as a result my symptoms were very mild. I started to think about having children about a year later, and I mentioned it to my Rheumatologist. She explained that the RA will probably go into remission during pregnancy, but I would likely have a flare up post-partum.

My husband and I had desperately always wanted children and planned to have a big family. I think because of the state of my disease at that time, I was led into a happy ignorance about how my RA would affect my ability to have children or to parent. I thought that I would be able to cope since I hadn't really experienced bad pain. I had good family support, and a medical background. I also did quite a bit of my own research when I first got RA I'd say we made the decision to have a child knowingly in the end.

My pregnancy was exactly as my Rheumatologist had predicted. I had no pain; no symptoms and I wasn't on any kind of medication. However, exactly eight weeks after I gave birth I woke up in terrible pain, like I was in a completely different body. It was very difficult because my baby was eight weeks old and, like any normal baby, wasn't sleeping well. My Rheumatologist put me onto corticosteroid prednisone straight away and after two days the pain had subsided quite a lot. I remember thinking that I have never known medication to change one's life so much. I was breastfeeding at the time but was able to stay on a dose of prednisone that was safe for the baby.The flare up lasted a couple of months and then I was able to come off prednisone, while still continuing to breastfeed. When my little one was about 12 months old, my husband and I started to think about having another baby. This time I did a lot more research, having experienced the pain and knowing how bad it could get. Having a big family had always been my dream, and all of a sudden, I really had to look at it and see whether it was the best thing for me and my family. I got into contact with a young women's support group because I just wanted to talk with other mums.

> "Although It was difficult to accept that we weren't going to have any more children I realised that it was important to not dwell on what I didn't have but to cherish what I dohave. We were incredibly lucky to have two healthy beautiful children."

My second pregnancy followed the exact same pattern as my first. I went into remission and felt fantastic, then eight weeks later, another flare up. This time though, I was not able to come off my medications and have been on them ever since. A couple of years after my second child was born I spoke to my Rheumatologist about having a third child, but she recommended not to. I am glad she was blunt with me because it was such an emotive process and I needed to be told the hard facts. My RA was a lot worse when the children were very young, which was hard to cope with, but I had a lot of support from family, friends and certainly my husband, and this was so important for me. I certainly have no regrets.

Summary of Facts

Positive Facts

- RA does not prevent one from having children.
- RA generally does not affect fertility.
- The majority of women with RA (75%) will experience some relief from RA symptoms during pregnancy.
- Pregnancy does not contribute to disability in RA.
- RA does not increase the risk of miscarriage or birth defects.
- Some medicines can still be taken during pregnancy if needed and as determined by a Rheumatologist.
- Women with RA can consider different methods of feeding their baby according to their individual needs.
- A strong network of friends, family and health professionals can provide support and assistance before, during and after pregnancy.
- The chance of a child developing RA is relatively small.

Negative Facts

- 25% of women may have the same or worse RA symptoms during pregnancy.
- 90% of women experience relapse or flare up of symptoms within 3-4 months after birth.
- Women with RA have slightly higher rates of some complications during pregnancy and delivery than women without RA.
- Most medicines cannot be taken during pregnancy and breastfeeding.
- Women may need to stay off their medicines if they choose to breastfeed, which may impact their levels of pain and disability.
- Some women with RA may have difficulties with the physical aspects of parenting.

Decision Steps

Women may think that there are only two motherhood choices: to have or not to have children. However, those two broad options may be further broken into a number of options.

For example, you may decide not to have children for now, until your RA is better managed, or when you are a bit older. If you do decide to have children, you may then consider if you would have one or more children.

Your decision may also be influenced by the availability of support networks.

It is important to consider these options with your partner (or close family member/s).

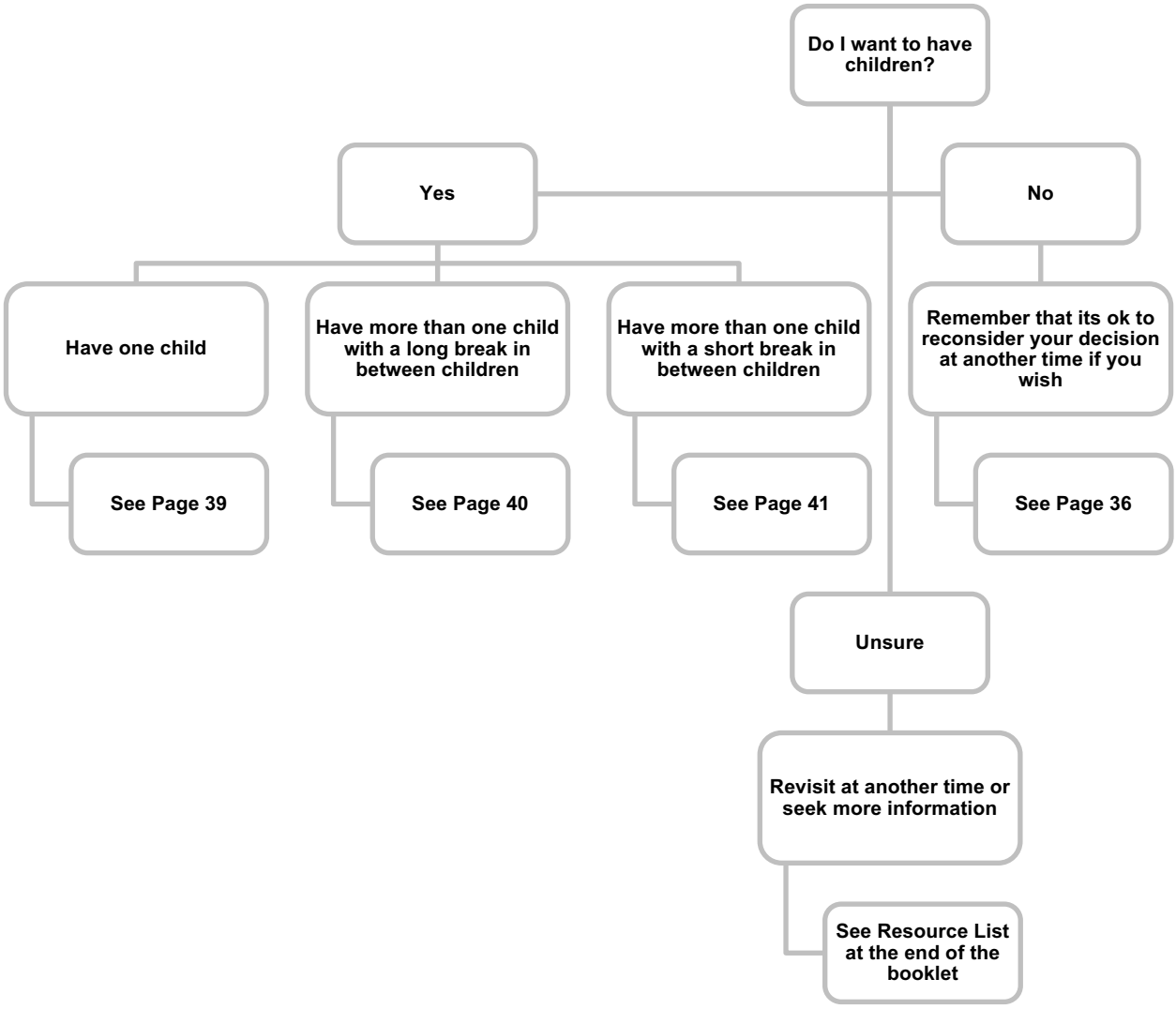
Remember it is okay to reconsider your decisions over time.

To help you make a decision about motherhood, it is important to:

1. **Consider the pros and cons of different options.** The next few pages are provided to help you explore your choices. They build on the information included in this booklet. Each option allows you to fill in your own pros and cons and to rate your concern in relation to each issue.
2. **Consult with your significant others**. On page 42 you'll find a worksheet to help identify who is important to you in making this decision.
3. **Identify what else you need to know to help you decide.** More worksheets are provided on pages 43-35 as well as a list of resources and services that may help you**.**
4. **Talk to your Rheumatologist**. It is important to consult with your rheumatologist about your options. It is the best place to provide you with relevant information and to engage in shared decision making.

Decision Steps

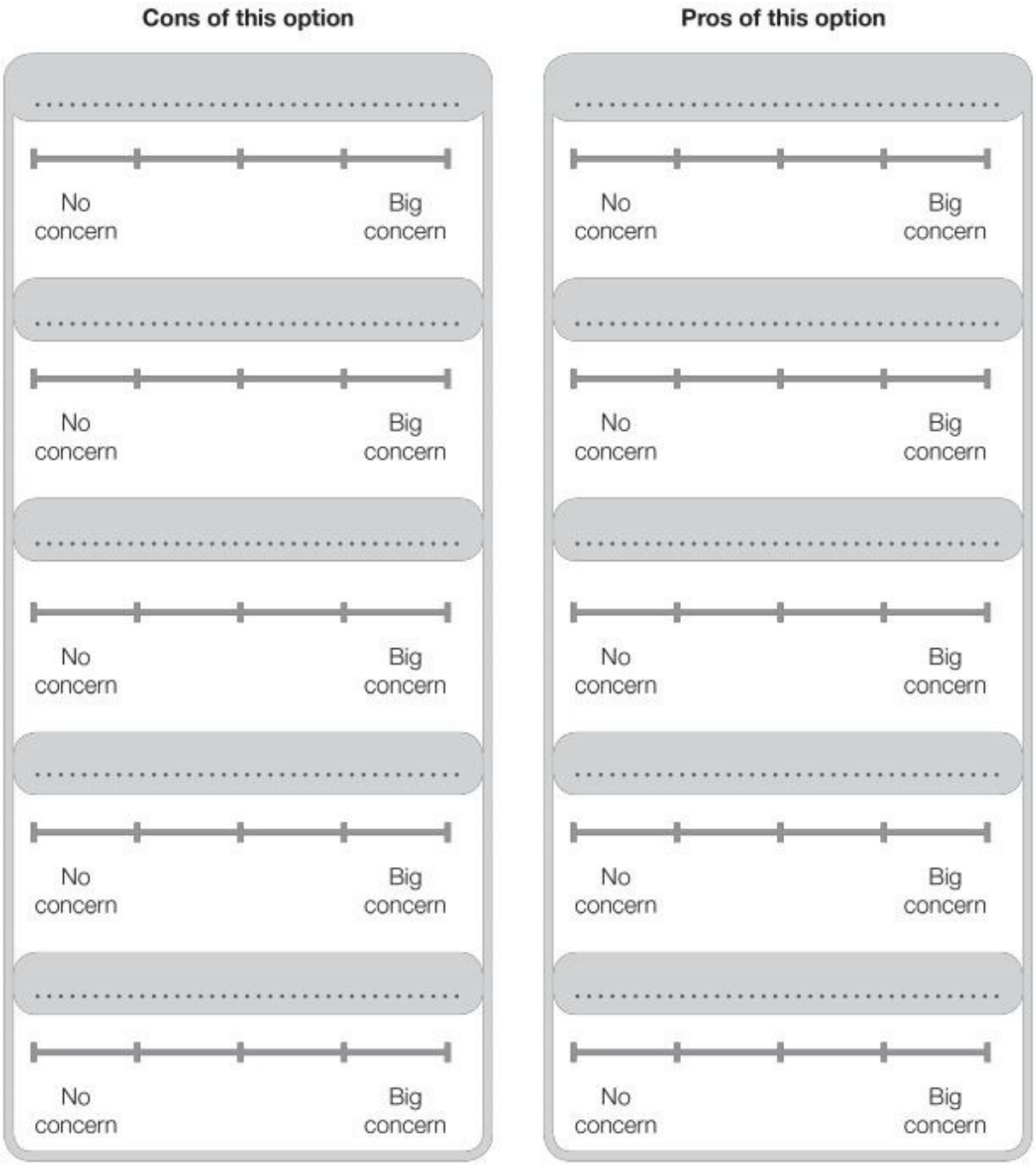
Reviewing your options



Decision Steps

Option 1: No (more) children

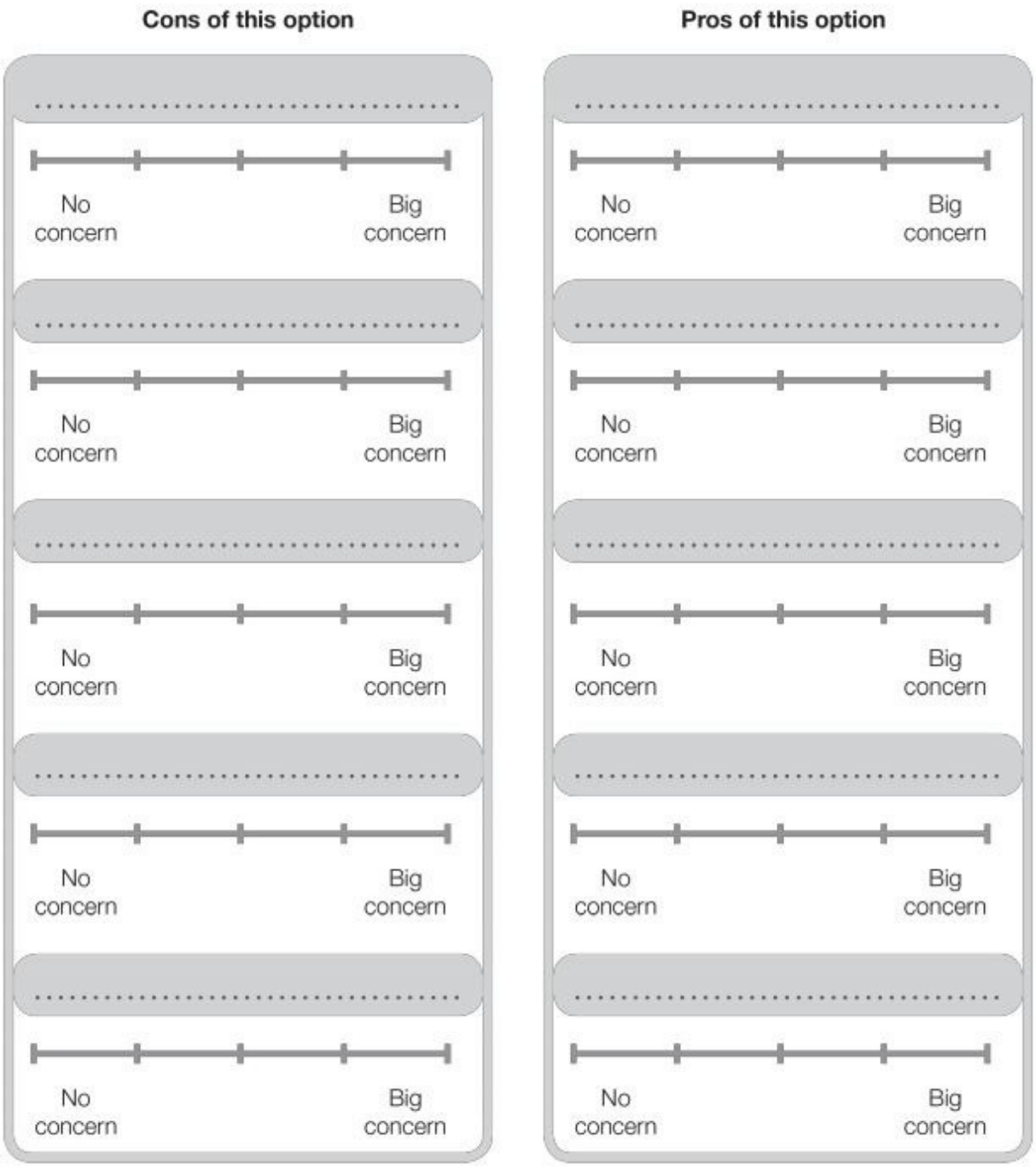
You may like to consider pros and cons of this option in terms of your health, level of support from your partner/family members, implications for your RA treatment, or anything else that is important to you.



Decision Steps

Option 2: Have only one (more) child

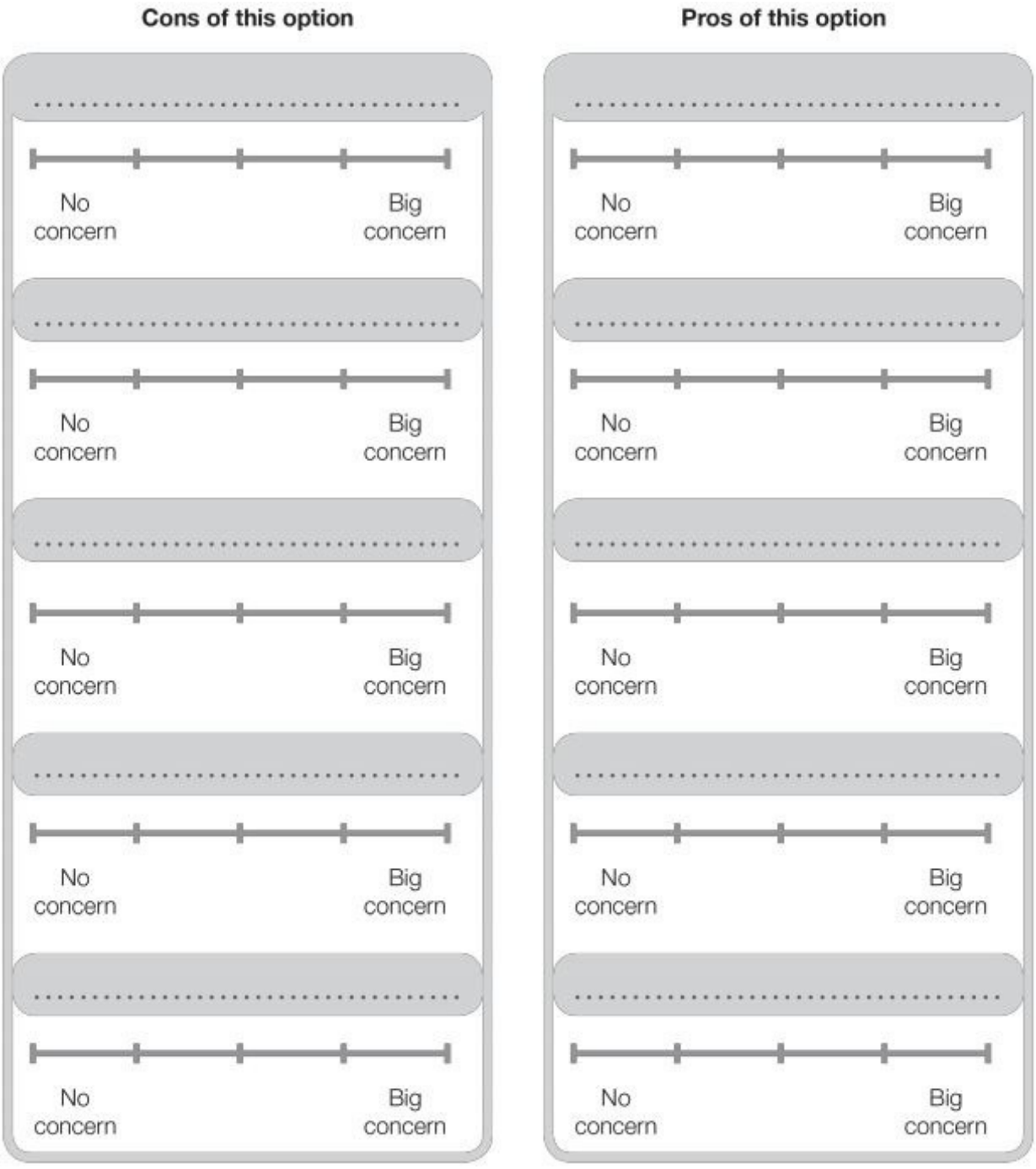
You may like to consider pros and cons of this option in terms of your health, level of support from your partner/family members, implications for your RA treatment, or anything else that is important to you.



Decision Steps

Option 3: Have more than one child, taking a long break between children

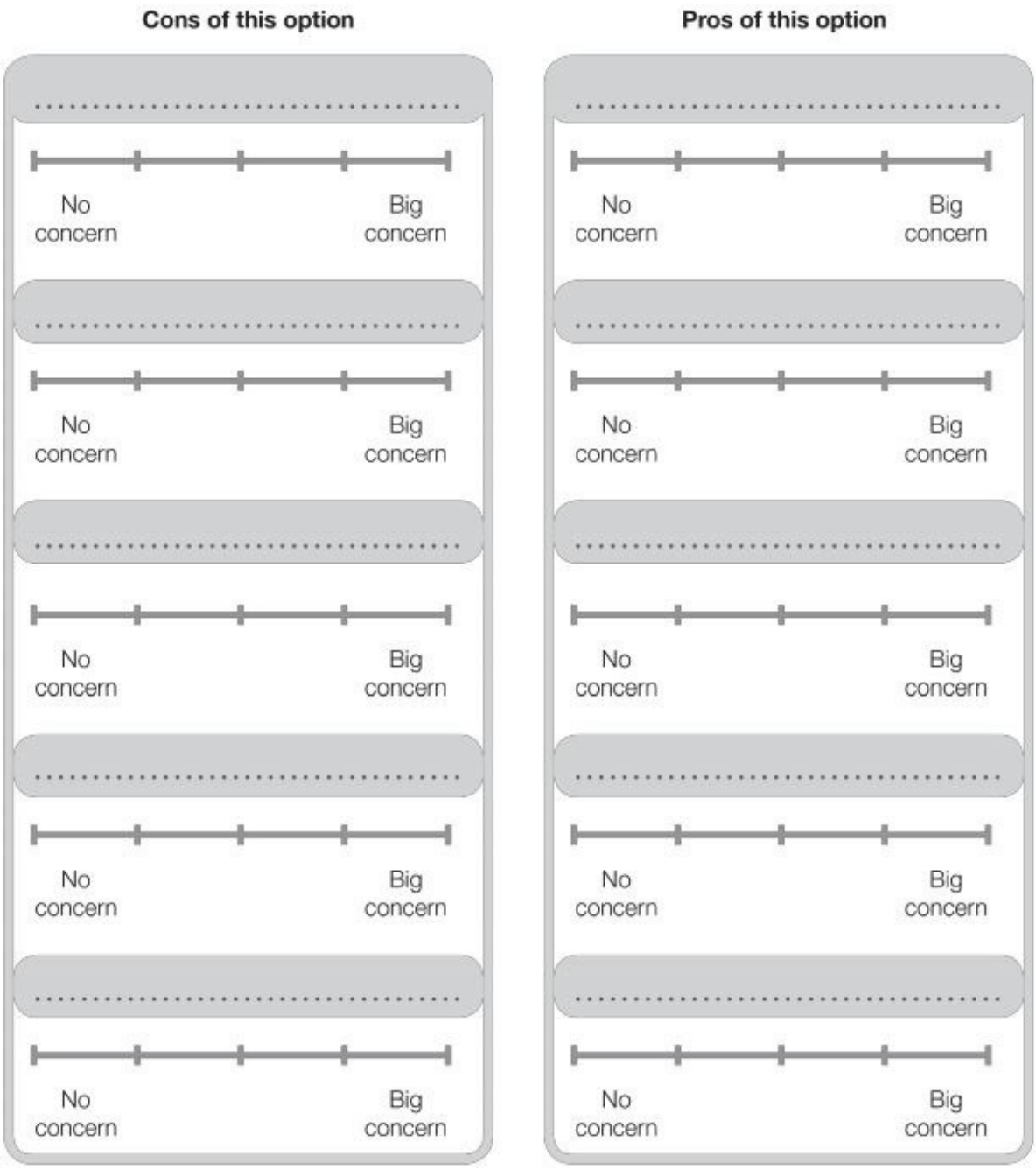
You may like to consider pros and cons of this option in terms of your health, level of support from your partner/family members, implications for your RA treatment, or anything else that is important to you.



Decision Steps

Option 4: Have more than one child, taking a short break between children*

You may like to consider pros and cons of this option in terms of your health, level of support from your partner/family members, implications for your RA treatment, or anything else that is important to you.



*This is a period of time insufficient to re-establish your medicine regime.

My Support Network

Once you have considered all the above information and possible options, you areencouraged to think about what is important to you, how your significant others may help you and how supported you feel in your decision.

List the important people (in addition to your Rheumatologist) whose opinions matter most to you in this decision.	Indicate whether or not you have spoken to them about your decision.	Indicate to what degree this person has supported your decision.
Partner	Yes / No	No / Somewhat / Yes
_____	Yes / No	No / Somewhat / Yes
_____	Yes / No	No / Somewhat / Yes
_____	Yes / No	No / Somewhat / Yes
_____	Yes / No	No / Somewhat / Yes
_____	Yes / No	No / Somewhat / Yes

Your Notes:

Checklist

Identify what else you need to know to help you decide.

You may now like to identify where you are at in terms of information, values, support and your feelings.

What I know	Yes	No	Unsure
Do I know enough about the impact of RA on pregnancy?	☐	☐	☐
Do I know enough about the impact of pregnancy and breast feeding on RA?	☐	☐	☐
Do I know enough about the impact of medicine on pregnancy and breast feeding?	☐	☐	☐
Do I know the pros of each option?	☐	☐	☐
Do I know the cons of each option?	☐	☐	☐
What is important to me	**Yes**	**No**	**Unsure**
Do I know which pros are the most important to me?	☐	☐	☐
Do I know which cons are the most important to me?	☐	☐	☐
What support I have	**Yes**	**No**	**Unsure**
Do I have enough support from significant others to make a decision?	☐	☐	☐
Am I pressured by others in my decision making?	☐	☐	☐
Have I had enough advice to make a decision?	☐	☐	☐
How sure I feel	**Yes**	**No**	**Unsure**
Am I clear about what is the best decision for me?	☐	☐	☐
Am I sure about what is the best decision for me?	☐	☐	☐

Checklist

Your notes

Remember it is okay to ask questions, your doctor welcomes them. It helps to write down your questions before you see your doctor as they are easy to forget. Write in the space below any questions you may like to ask your Rheumatologist/specialist or other health professionals.

Where to Next

Your Rheumatologist/specialist's notes

Your Rheumatologist/specialist or other health professionals may like to summaries below some of the key points from your talk with them.

> “Hearing other people's experiences, hearing information from health professionals anddoing my own research all helped in making the decision.”
>
> *Woman with RA*

Depending on your decision, you may like to outline what you plan to do next.

We hope this Decision Aid Tool has provided you with a good starting point to help you make the best possible decision for you.

Information Resources

Australia

Arthritis Information & Resources

1 , Arthritis Australia
Phone: 1800-011-041
www.arthritisaustralia.org.au

2. Australian Rheumatology Association
Phone: 02-9252-2356
www.rheumatology.org.au

Disability Resources

3. Disability Discrimination Act
www.humanrights.gov.au/employers/good-practice-good-business-factsheets/disability-discrimination

4. National Disability Insurance Scheme
Phone: 1800-800-110
www.ndis.gov.au

5. Independent Living Centres Australia
Phone: 1300-885-886
https://ilcaustralia.org.au/

Women's Health

6. Australian Women's Health Network
www.awhn.org.au

7. Family Planning Alliance Australia
https://www.familyplanningallianceaustralia.org.au/

Medicines in Pregnancy & Breastfeeding Resources

8. NPS MedicineWise
Phone: 1300 MEDICINE (1300-633-424)
www.nps.org.au

9. Consumer Medicine Information
www.medicines.org.au

10. Medicines in Pregnancy and Breastfeeding Services (by State):

a. New South Wales:
Mothersafe Royal Hospital for Women
Randwick
Phone: 02-9382-6070 (Sydney) or
1800-647-848 (Non-Sydney)
https://www.seslhd.health.nsw.gov.au/royal-hospital-for-women/services-clinics/directory/mothersafe

b. Queensland:
Medication Helpline:
13 HEALTH (1343-2584)
https://www.qld.gov.au/health/contacts/advice/13health

c. Victoria:
Nurse on Call
Phone: 1300-606-024
www.betterhealth.vic.gov.au/health/healthyliving/pregnancy-medication-drugs-and-alcohol

d. Western Australia:
Obstetric Medicines Information Service
Phone: 08-6458-2723

e. South Australia:
24 Hour Parent Helpline:
Ph: 1300-364-100
Medicines and Drug Information Centre:
Ph: 08-8161-7222

Pregnancy & Parenting Resources

11. Pregnancy, Birth and Baby Helpline
Phone: 1800-882-436
www.pregnancybirthbaby.org.au

12. Tresillian
Phone: 1300-272-736
www.tresillian.org.au

13. The Australian Parenting Website
www.raisingchildren.net.au

Mental Health Resources

14. Australian Psychological Society (APS)
Find a Psychologist Service:
Phone: 1800-333-497
https://www.psychology.org.au/Find-a-Psychologist

15. Post and Antenatal Depression Association (PANDA)
Phone: 1300-726-306
www.panda.org.au

16. Beyond Blue
Phone: 1300-224-636
www.beyondblue.org.au

17. Black Dog Institute
www.blackdoginstitute.org.au

Information Resources

New Zealand

Arthritis Information & Resources

1. Arthritis New Zealand:
   Phone: 0800-663-463
   http://www.arthritis.org.nz/

2. NZ Rheumatology Association:
   https://www.rheumatology.org.nz/home

Disability Resources

3. Ministry of Health:
   24 Hour Healthline: 0800-611-116
   Disability Support Information: 0800-855-066
   http://www.health.govt.nz/

4. Support & Service for People with Physical Disability:
   Phone: 0800-227-2255
   http://www.ccsdisabilityaction.org.nz/

Pregnancy & Breastfeeding Resources

5. Maternity Services Consumer Council:Phone: 022-421-6008
   https://maternity.org.nz/

6. Miscarriage Support:
   Support line: 09-378-4060
   http://www.miscarriagesupport.org.nz/

7. The New Zealand Breastfeeding Authority:
   Phone:03-3572-072 http://www.babyfriendly.org.nz/

8. Consumer Medicine Information:
   Phone: 04-819-6800
   http://www.medsafe.govt.nz/

Mental Health Resources

9. NZ Psychological Society, Find a Psychologist:
   http://www.psychology.org.nz/Find-Psychologist

10. The Postnatal Depression Family Trust NZ:
    https://www.mothersmatter.nz/

United Kingdom

Arthritis Information & Resources

1 , The British Society for Rheumatology:
   Phone: 2078-420-900
   http://www.rheumatology.org.uk/

2. National Rheumatoid Arthritis Society:
   Free Phone Helpline: 0800-298-7650 http://www.nras.org.uk/

3. Empowering People with Arthritis:
   Free helpline: 0800-5200-520
   http://www.versusarthritis.org

Pregnancy & Breastfeeding Resources

4. National Breastfeeding Helpline:
   Phone: 0300100 0212
   https://www.breastfeedingnetwork.org.uk/drugs-factsheets/

5. Consumer Medicine Information:
   www.medicines.org.uk

Mental Health Resources

6. British Psychological Society, Find a Psychologist:
   https://www.bps.org.uk/public/find-psychologist/

Information Resources

United States

Arthritis Information & Resources

1. USA Arthritis Foundation:
   Phone: 1-800-283-7800
   https://www.arthritis.org/

2. American College of Rheumatology:
   Phone: 404-633-3777
   https://www.rheumatology.org/

3. Centers for Disease Control and Prevention, Arthritis Information:
   24 Hour Info Line: 800-232-4636
   https://www.cdc.gov/arthritis/

Disability Resources

4. Americans With Disabilities Act:
   Info Une: 1-800-514-0301
   https://www.ada.gov/

Women's Health

9. The Office of Women's Health:
   Phone: 1-800-994-9662
   https://www.womenshealth.gov/

10. National Women's Health Resource Center: Phone: 1-877-986-9472
    https://www.healthywomen.org/

Pregnancy & Breastfeeding Resources

11. Drugs in Pregnancy & Breastfeeding
    http://www.perinatology.com/exposures/druglist.htm

12. Drugs and Lactation Database (LactMed)
    https://www.ncbi.nlm.nih.gov/books/NBK501922/

Mental Health Resources

13. National Institute of Mental Health:
    Phone: 1-866-615-6464
    https://www.nimh.nih.gov/

14. American Psychological Association Psychologist Locator Service:
    Phone: 800-374-2721
    https://locator.apa.org/

15. Postnatal Depression Information & Resources:
    Phone: 1800-944-4773
    https://www.postpartum.net/

Canada

Arthritis Information & Resources

1. The Arthritis Society Canada: Phone: 1800-321-1433
   https://www.arthritis.ca/

2. Arthritis Research Centre Canada:
   https://www.arthritisresearch.ca/

Disability Resources

3. Disabled Women's Network Canada:
   Info Line: 1-866-396-0074
   https://www.dawncanada.net/

Women's Health

4. Canadian Society of Obstetricians & Gynecologists, Women's Health
   Phone: 1800-561-2416
   https://www.sogc.org/

5. Women's Health Matters, Women's College Research Institute:
   https://www.womenshealthmatters.ca/

Pregnancy & Breastfeeding Information

6. Pregnancy Care Canada
   Info Line: 1-866-845-2151
   https://pregnancycarecanada.ca/

7. Medications during pregnancy – Healthlink
   https://www.healthlinkbc.ca/health-topics/uf9707

Mental Health Resources

8. Canadian Psychological Association:
   Info Line: 1-888-472-0657
   https://www.cpa.ca/

9. Pacific Postpartum Support Society Canada:
   Support Line: 604-255-7999
   https://www.postpartum.org/

Selected Key References

Ackerman, I. N., Bohensky, M. A., Pratt, C., Gorelik, A., & Liew, D. (2016). *Counting the cost: The current and future burden of arthritis*. Broadway: Report prepared for Arthritis Australia. Retrieved from https://arthritisaustralia.com.au/wordpress/wp-content/uploads/2017/09/Final-Counting-the-Costs_Part1_MAY2016.pdf

Ackerman, I. N., Ngian, G.-S., Van Doornum, S., & Briggs, A. M. (2016). A systematic review of interventions to improve knowledge and self-management skills concerning contraception, pregnancy and breastfeeding in people with rheumatoid arthritis. *Clinical Rheumatology, 35*(1), 33-41. doi:10.1007/s10067-015-3131-7

Australian Bureau of Statistics. (2016). *Causes of death, Australia*. Cat. no. 3303.0. Retrieved from http://www.abs.gov.au/ausstats/abs@.nsf/0/47E19CA15036B04BCA2577570014668B?Opendocument

Australian institute of Health and Welfare. (2009). A picture of rheumatoid arthritis in Australia. Arthritis series no. 9. Cat.no. PHE 110. Canbe11a: AIHW. Retrieved from https://www.aihw.gov.au/getmedia/f557085b-6eef-40be-85a9-2bd18746c4e1/phe-110-10524.pdf.aspx?inline=true

Australian Institute of Health and Welfare 2015. Musculoskeletal fact sheet: rheumatoid arthritis. Arthritis series no. 24. Cat. no. PHE 188. Canberra: AIHW. Retrieved from https://www.aihw.gov.au/getmedia/1e295637-e5fb-4059-a1d8-eb3936cfa7a9/phe188-rheumatoid-arthritis-factsheet.pdf.aspx?inline=true

Australian Institute of Health and Welfare (2017). Rheumatoid arthritis. Cat. No: WEB 62. Retrieved from https://www.aihw.gov.au/reports/chronic-musculoskeletal-conditions/rheumatoid-arthritis/contents/what-is-rheumatoid-arthritis

Australian Institute of Health and Welfare 2018. Australia's mothers and babies 2016—in brief. Perinatal statistics series no. 34. Cat. no. PER 97. Canberra: AIHW.

Australian Rheumatology Association. (2017). Notes on prescribing medications for rheumatic diseases in pregnancy. Sydney: Australian Rheumatology Association.

Barbhaiya, M., & Bermas, B. L. (2013). Evaluation and management of systemic lupus erythematosus and rheumatoid arthritis during pregnancy. *Clinical Immunology (Orlando, Fla.), 149*(2), 225-235. doi:10.1016/j.clim.2013.05.006

Bermas, B. L. (2014). Non-steroidal anti inflammatory drugs, glucocorticoids and disease modifying anti-rheumatic drugs for the management of rheumatoid arthritis before and during pregnancy. *Current Opinion in Rheumatology, 26*(3), 334-340.

Brouwer, J., Fleurbaaij, R., Hazes, J. M. W., Dolhain, R. J. E. M., & Laven, J. S. E. (2017). Subfertility in Women With Rheumatoid Arthritis and the Outcome of Fertility Assessments. *Arthritis Care & Research, 69*(8), 1142-1149. doi:10.1002/acr.23124

Chen, H., Wang, J., Zhou, W., Yin, H., & Wang, M. (2015). Breastfeeding and Risk of Rheumatoid Arthritis: A Systematic Review and Metaanalysis. *The Journal Of Rheumatology, 42*(9), 1563-1569.

Costenbader, K. H., Gay, S., Alarcón-Riquelme, M. E., Iaccarino, L., & Doria, A. (2012). Genes, epigenetic regulation and environmental factors: Which is the most relevant in developing autoimmune diseases? *Autoimmunity Reviews, 11*(8), 604-609.

Covic, T., Cumming, S. R., Pallant, J. F., Manolios, N., Emery, P., Conaghan, P. G., & Tennant, A. (2012). Depression and anxiety in patients with rheumatoid arthritis: Prevalence rates based on a comparison of the Depression, Anxiety and Stress Scale (DASS) and the hospital, Anxiety and Depression Scale (HADS). *BMC Psychiatry, 12*, 6-6.

De Man, Y. A., Dolhain, R. J. E. M., & Hazes, J. M. W. (2014). Disease activity or remission of rheumatoid arthritis before, during and following pregnancy. *Current Opinion in Rheumatology, 26*(3), 329-333.

Flint, J., et al. (2016). BSR and BHPR guideline on prescribing drugs in pregnancy and breastfeeding-Part I: standard and biologic disease modifying anti-rheumatic drugs and corticosteroids. *Rheumatology* (Oxford), *55*(9), 1693-1697.

Förger, F., & Villiger, P. M. (2016). Treatment of rheumatoid arthritis during pregnancy: present and future. *Expert Review Of Clinical Immunology, 12*(9), 937-944. doi:10.1080/1744666X.2016.1184973

Förger, F. (2017). Treatment with biologics during pregnancy in patients with rheumatic diseases. *Reumatologia, 55*(2), 57-58.

Gerosa, M., Schioppo, T., & Meroni, P. L. (2016). Challenges and treatment options for rheumatoid arthritis during pregnancy. *Expert Opinion On Pharmacotherapy, 17*(11), 1539-1547. doi:10.1080/14656566.2016.1197204

Götestam Skorpen, C., et al. (2016). The EULAR points to consider for use of antirheumatic drugs before pregnancy, and during pregnancy and lactation. *Annals Of The Rheumatic Diseases, 75*(5), 795.

Higgins, K. S., Birnie, K. A., Chambers, C. T., Wilson, A. C., Caes, L., Clark, A. J., . . . Campbell-Yeo, M. (2015). Offspring of Parents with Chronic Pain: A Systematic Review and Meta-Analysis of Pain, Health, Psychological, and Family Outcomes. *Pain, 156*(11), 2256-2266. doi:10.1097/j.pain.0000000000000293

Selected Key References

Ince-Askan, H., et al. (2017). Identifying Clinical Factors Associated With Low Disease Activity and Remission of Rheumatoid Arthritis During Pregnancy. *Arthritis Care & Research, 69*(9), 1297-1303.

Jansenn, N. M., & Genta, M. S. (2000). The effects of immunosuppressive and anti-inflammatory medications on fertility, pregnancy, and lactation. *Archives of Internal Medicine, 160*(5), 610-619.

Kavanaugh, A., et al. (2015). Proceedings From the American College of Rheumatology Reproductive Health Summit: The Management of Fertility, Pregnancy, and Lactation in Women With Autoimmune and Systemic Inflammatory Diseases. *Arthritis Care & Research*, *67*(3), 313-325.

Krause, M. L., et al. (2014). Use of DMARDs and biologics during pregnancy and lactation in rheumatoid arthritis: what the rheumatologist needs to know. *Therapeutic Advances In Musculoskeletal Disease, 6*(5), 169-184.

Leahy-Warren, P., McCarthy, G., & Corcoran, P. (2012). First-time mothers: social support, maternal parental self-efficacy and postnatal depression. *Journal of Clinical Nursing, 21*(3-4), 388-397.

Lin, H. C., Chen, S. F., Lin, H. C., & Chen, Y. H. (2010). Increased risk of adverse pregnancy outcomes in women with rheumatoid arthritis: A nationwide population-based study. *Annals of the Rheumatic Diseases, 69*(4), 715-717.

Matcham, F., Norton, S., Scott, D. L., Steer, S., & Hotopf, M. (2016). Symptoms of depression and anxiety predict treatment response and long-term physical health outcomes in rheumatoid arthritis: secondary analysis of a randomized controlled trial. *Rheumatology (Oxford), 55*(2), 268-278. doi:10.1093/rheumatology/kev306

Matcham, F., et al. (2016). Are depression and anxiety associated with disease activity in rheumatoid arthritis? A prospective study. *BMC Musculoskeletal Disorders, 17*(1), 155.

Meloncelli, S., Crimmins, G., Briggs, A. M., & Bywaters, L. (2015). *Explore, document and share coping strategies and support mechanisms employed by mothers with rheumatoid arthritis.* Melbourne, Australia: Arthritis and Osteoporosis Victoria.

Meade, T., Sharpe, L., Hallab, L., Aspanell, D., & Manolios, N. (2013). Navigating motherhood choices in the context of rheumatoid arthritis: Women's stories. *Musculoskeletal Care, 11*(2), 73-82.

Meade, T., Dowswell, E., Manolios, N., & Sharpe, L. (2015). The motherhood choices decision aid for women with rheumatoid arthritis increases knowledge and reduces decisional conflict: a randomized controlled trial. *BMC Musculoskeletal Disorders*, *16*:*260*. https://doi.org/10.1186/s12891-015-0713-0

Mouyis, M., Flint, J. D., & Giles, I. P. (2018). Safety of anti-rheumatic drugs in men trying to conceive: A systematic review and analysis of published evidence. *Seminars In Arthritis And Rheumatism*. doi:https://doi.org/10.1016/j.semarthrit.2018.07.011

Ngian, G.-S., Briggs, A. M., Ackerman, I. N., & Van Doornum, S. (2016). Safety of anti-rheumatic drugs for rheumatoid arthritis in pregnancy and lactation. *International Journal Of Rheumatic Diseases, 19*(9), 834-843. doi:10.1111/1756-185X.12860

Ngian, G.-S., Briggs, A. M., Ackerman, I. N., & Van Doornum, S. (2016). Management of pregnancy in women with rheumatoid arthritis. *The Medical Journal Of Australia, 204*(2), 62-63.

Østensen, M. & Villiger, P. M. (2007). The remission of rheumatoid arthritis during pregnancy. *Seminars In immunopathology*, 29, 185-191.

Østensen, M. (2014). Safety issues of biologics in pregnant patients with rheumatic diseases. *Annals of the New York Academy of Sciences, 1317*(1), 32-38.

Østensen, M. (2014). Contraception and pregnancy counselling in rheumatoid arthritis. *Current Opinion In Rheumatology 26*(3), 302-307.

Østensen, M., Andreoli, L., Brucato, A., Cetin, I., Chambers, C., Clowse, M. E., . . . von Wolff, M. (2015). State of the art: Reproduction and pregnancy in rheumatic diseases. *Autoimmun Rev, 14*(5), 376-386.

Proudman, S. M., James, M. J., Spargo, L. D., Metcalf, R. G., Sullivan, T. R., Rischmueller, M., ... Cleland, L. G. (2013). Fish oil in recent onset rheumatoid arthritis: a randomised, double-blind controlled trial within algorithm-based drug use. *Annals of the Rheumatic Diseases, 74*(1), 89-95.

Redshaw M, Malouf R, Gao H, Gray R. (2013). Women with disability: the experience of maternity care during pregnancy, labour and birth and the postnatal period. *BMC Pregnancy Childbirth, 13(174).* doi:10.1186/1471-2393-13-174.

Singh, J. A., et al. (2016). 2015 American College of Rheumatology Guideline for the Treatment of Rheumatoid Arthritis. *Arthritis Care & Research, 68*(1): 1-25.

Selected Key References

Smolen, J. S., et al. (2016). EULAR recommendations for the management of rheumatoid arthritis with synthetic and biological disease-modifying antirheumatic drugs: 2016 update. *Annals of the Rheumatic Diseases, 79(6),* 1468-2060.

Vinet, E., et al. (2018). Serious infections in rheumatoid arthritis offspring exposed to Tumor Necrosis Factor Inhibitors: A cohort study. *Arthritis & Rheumatology, 70(10),* 1565-1571.

Williams, M. and E. F. Chakravarty (2014). Rheumatoid arthritis and pregnancy: impediments to optimal management of both biologic use before, during and after pregnancy. *Current Opinion In Rheumatology, 26*(3), 341-346.

Wilsdon, T. D., & Hill, C. L. (2017). Managing drug treatment rheumatoid arthritis. *Australian Prescriber, 40*(2), 51-5.