



# Explore, document and share coping strategies and support mechanisms employed by mothers with rheumatoid arthritis

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## Project team

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## Background

Rheumatoid arthritis (RA) is an autoimmune disease associated with systemic inflammation that causes joint pain and destruction if left untreated, especially in the small joints in the hands and feet. Other organs of the body may also be affected. Key facts about RA:

- In 2011-12 445,000 Australians reported having RA<sup>1</sup>
- 5 out of 8 people with RA are women<sup>1</sup>
- Onset commonly occurs between the ages 35-64 years.<sup>2</sup>
- The prevalence of RA is expected to rise by 40% in Australia by 2032.<sup>3</sup>

RA can have an impact on women in their reproductive years<sup>4</sup>, yet the literature suggests that mothers with RA feel let down by a health system that fails to understand their unique needs alongside the needs of their families<sup>4-6</sup>. In particular Meade et al<sup>4</sup> identified that mothers' individual support requirements need to be identified in order to ensure that they, and their families, receive appropriate physical and emotional support and information from allied health professionals such as maternal health nurses, GP's, rheumatologists and occupational therapists. Research undertaken by Ackerman et al<sup>7</sup> concurs, reporting that mothers with RA report a lack of information regarding management of their RA during pregnancy, breastfeeding and early parenting. The research also identified an urgent need to address the specific needs of younger women and mothers with RA.

As well as joint damage and functional disability, people living with RA are more likely to experience psychological impacts such as depression and anxiety<sup>1</sup>. Not only is it important to address the physical impairments associated with RA but it is vital to provide support for mothers and women regarding psychological wellbeing. Currently the majority of health services directed towards women with RA have a biomedical focus, leaving a burden-service gap in the psychological domain.

This research project, supported by Arthritis and Osteoporosis Victoria (A&OV) and the University of the Sunshine Coast (USC) was designed to capture and share the emotional, psychological and practical strategies that some mothers with RA have developed, that could in turn be used to support other mothers with RA. It aligns with recent EULAR recommendations for patient education in people with inflammatory arthritis.<sup>8</sup>

## Purpose

The purpose of this project was to document and share the personal stories of mothers with RA, and to create a resource to support other mothers to cope with the impacts of RA alongside parenting and maintaining other life roles such as employment, study and interpersonal relationships.

## Project aims

The overall aim of the project was to fill a current gap in knowledge and extend on current research relating to women with RA with a specific focus on mothers. These aims included:

- recording and sharing diverse coping strategies and lived experiences of the mothers with RA
- empowering and educating mothers with RA by sharing not only practical strategies but also psychological strategies to manage the stress and pain associated with RA (particularly combined with managing other roles such as parenting, relationships and paid working roles)
- educating and empowering families, friends, employers and health practitioners supporting mothers with RA by sharing individualised, specific strategies as suggested by the mothers themselves
- addressing a gap in knowledge and service provision by exploring how mothers with RA cope and are supported.

## Methods

Five mothers with RA living on the Sunshine Coast, Queensland, were recruited through local media and through local contacts. Their details at filming were:

- aged 33 – 46 years
- they had 2-3 children between the ages of 4 months and 25 years
- four mothers were married, one was single
- all except one was employed outside the home.

They were contacted to discuss the project individually. They also:

- received a Research Project Information Sheet (RPIS)<sup>1</sup> and Consent Form<sup>2</sup> which was fully explained and then signed by each participant. The RPIS identified explicitly that the participant could withdraw from the project at any time without penalty
- were contacted by phone to discuss expectations and answer any questions
- were free to contact researchers at any time
- could withdraw filmed footage from the project at any time without penalty

Filming was undertaken in a recording studio in Queensland. Participants were able to tell their story in their own way. The focus of the interviews was around coping strategies, both physical and psychological, and the participant's main supports. Researcher's questions were kept to a minimum so that the mothers' stories were expressed in their words.

The final audio-visual product was edited to include the stories and strategies of four mothers. Footage was sent to A&OV for review. Feedback was provided to USC researchers, footage was re-edited and returned to A&OV to be hosted on their website.

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<sup>1</sup> See Appendix A for Research Project Information Sheet

<sup>2</sup> See Appendix B for Consent Form

## Key findings

In this project audio-visual footage captured the first-hand experiences, resilience and practical wisdom of mothers with RA. The footage was produced as an accessible resource to educate and empower mothers with RA, health professionals working with mothers with RA, and the families and friends of these mothers.

Three central themes emerged within their stories. They were:

- the personal narrative of living and parenting with RA
- the practical strategies mothers with RA employ
- the psychological and emotional strategies mothers with RA use to cope.

## Personal narratives

The personal narratives of living with RA alongside parenting were shared as:

- each mother beginning with a description of her RA diagnosis which included shock, disbelief and distress. One participant discussed her relief at a final definitive diagnosis as she had had symptoms for years
- discussions of the emotional pressure that having RA placed on their lives (and their families)
- feelings of guilt at not fulfilling perceived roles such as that of being a mother, wife, employee
- stories of financial pressures due to factors such as increased health expenditure and compromised employment as a result of being diagnosed with RA;
- the women describing the importance of perseverance/persistence when parenting with RA.

*'I guess thinking back it was pretty hard to accept because I thought this is not going to last forever, this is something I can overcome, but it just kept getting worse.*

*I was told by doctors and specialists I wouldn't be able to do my degree...*

*and I guess I did go through a lot of emotional distress.'*

*- Mother, age 33, 2 children*

## Practical strategies

The practical strategies employed by these mothers with RA included:

- the specific ways in which they changed, held and carried their babies
- the use of baby slings to hold young babies safely was a common adaptation discussed (reducing the risk of dropping baby)
- using nappies, strollers or baby clothes that didn't have buttons or fasteners that required dexterity or strength in hands and wrists
- the safe environments they created for their children during a 'flare'
- the need to rest or pace activities during a 'flare'
- the use of aids such as a safe baby sleep pod<sup>3</sup> in the family bed
- healthy food choices and preparation (preparing multiple meals at once), encouraging 'mature behaviours' in children and encouraging them to assist in making lunches, chopping vegetables and completing domestic chores like running up and down stairs when mum couldn't
- parking nearer to one's destination if possible

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<sup>3</sup>Sleep pod - allows mothers to be close to baby when co-sleeping but keeps the baby protected from being rolled on or suffocated

- moving to a single story home as stairs were an impediment to one mother's coping
- exercise and relaxation techniques to minimise stress and manage pain
- the use of meditation, natural remedies, taking baths, reading in a quiet spot and watching movies with their children as both practical and psychological support strategies
- strategies used to cope emotionally with the physical pain and exhaustion experienced (also feelings of guilt, anger, isolation)
- sharing a 'take home message' to other mothers with RA and their supportive 'team' (spouses, family, friends, employers, practitioners)

*'You just did learn to adapt...when I was pregnant with my 2nd I set up a mattress on the lounge floor and my eldest would just play on the floor all day... you just make these adaptations out of necessity.'*

*- Mother, age 37, 2 children*

*'I parked closer. I loaded both kids up into the same pram... I had to get an easy pram. I found it hard to get the big two seater pram out.'*

*- Mother, age 35, 3 children*

### Psychological and emotional strategies

A common theme that emerged from all the mothers' stories was the importance of having psychological coping strategies and a strong sense of self-belief in one's abilities. For example:

- every mother discussed the importance of 'self-care' practices which included exercise and rest that supported their physical and psychological well-being
- each mother suggested that having a positive outlook and surrounding themselves with positive RA stories helped them to stay resilient
- every participant provided a 'take home message' to other mothers with RA, each of which emphasised the importance of a positive attitude and self-belief
- most of the women discussed their reliance on family and friends for emotional support
- three participants discussed the importance of positive self-talk
- one mother emphasised becoming as informed as possible about RA and taking control of her own health as essential in order to cope with RA.

*'My husband is fantastic - he'll help whichever way he can. Sometimes it's hard for him if I'm a bawling mess. It's hard to understand the depth of it because you can't actually see it. He tries very hard and is very compassionate. I'm very lucky to have him.'*

*- Mother, age 35, 2 children*

*'Don't give up on yourself and don't say I can't just go and try. I love Zumba... I can do everything. My life is not full of negative RA stories anymore. I hear people tell me lots of positive arthritis stories...how they can wear high heels...'*

*- Mother, age 35, 3 children*

The footage can be viewed here: <http://www.arthritisvic.org.au/Useful-Information/About-Us/Video/Coping-Strategies-Mothers-with-RA>.

## Implications

The mothers' stories indicated how a diagnosis of RA often came with a rollercoaster of emotions including shock, grief and distress. This information is important for practitioners, family and friends and mothers themselves as it demonstrates the likely need for individualised, psychological support for mothers following a RA diagnosis.

Practical strategies, when shared, can provide tools for new mothers or women with RA contemplating pregnancy. Having a 'toolkit' of strategies for various situations can not only provide practical physical solutions but may also reduce feelings of anxiety and depression surrounding motherhood. Additionally, being able to successfully manage an issue such as how to safely hold, feed and settle your baby when one's hands may be painful and lacking dexterity could improve self-esteem and possibly reduce feelings of parental guilt. The efficacy of such tools now need to be examined.

## Conclusion

As demonstrated by the mothers' stories, the researchers were able to detect a common theme: effective practical strategies is associated with a greater sense of control for mothers with RA and improved psychological wellbeing. In sharing their stories, mothers outlined how being able to manage the impacts of RA alongside the demands of a mothering role, in their own individual way, had a positive impact on their psychological well-being and thus the well-being of their family. Mothers stated having practical strategies gave them a greater sense of control over life circumstances and empowered them. Involving mothers with RA to develop strategies to assist other mothers, as 'experts by experience', allows valuable wisdom to be shared.

## Future directions

The stories in this resource will be used to assist mothers with RA, respecting the intentions of the five mothers who shared their personal stories. The audio-visual resource are now co-hosted on the USC and A&OV websites - <http://www.arthritisvic.org.au/Useful-Information/About-Us/Video/Coping-Strategies-Mothers-with-RA>.

Future research should be directed towards examining the effectiveness of audio-visual resources and possibly extending their scope and formats.

## Arthritis and Osteoporosis Victoria: How we can help

At Arthritis and Osteoporosis Victoria, we have a range of services and programs to help you if you have rheumatoid arthritis:

- MSK Help Line. For information on living with rheumatoid arthritis, assistance navigating the complex health, disability and social services systems; information on community resources in the community, call our nurses on 1800 263 265 weekdays, or email [msk@arthritisvic.org.au](mailto:msk@arthritisvic.org.au).
- Library. We have resources on many different musculoskeletal conditions – including rheumatoid arthritis – as well as information on pregnancy, nutrition, exercise, pain management and treatment options, and a collection of rheumatology journals and newsletters. Access the library catalogue to see what's available - [www.arthritisvic.org.au/Useful-Information/Our-Services/Library](http://www.arthritisvic.org.au/Useful-Information/Our-Services/Library) or contact the librarian on 03 8531 8031 (toll free for country callers on 1800 263 265).
- Peer support groups across Victoria provide information, support and understanding to members. Go to the Arthritis Map - [www.arthritismap.com.au](http://www.arthritismap.com.au) - to find the details of groups in Victoria.
- Young Women's Arthritis Support Group is a group specifically for women with a musculoskeletal condition. Get information, support and understanding from people who understand what you are going through. Visit their Facebook page [www.facebook.com/ywasg](http://www.facebook.com/ywasg) for more information.
- Courses, seminars and webinars. Learn practical ways to live with rheumatoid arthritis. Details of upcoming events are listed on our website. [www.arthritisvic.org.au/Education-and-Events](http://www.arthritisvic.org.au/Education-and-Events)
- Website. Provides up to date information on issues important to people with musculoskeletal conditions: [www.arthritisvic.org.au](http://www.arthritisvic.org.au).

## Acknowledgements

This project, undertaken by USC researcher Shannyn Meloncelli and Dr Gail Crimmins, was supported in kind by the School of Communication and Creative Industries, Faculty of Arts and Business, USC, and by the mentorship of Associate Professor Andrew Briggs, Senior Advisor, A&OV. The project was financially supported by a partnership research grant from A&OV and a USC Office of Engagement grant. The audio-visual resources are co-owned, co-branded and are co-hosted by USC and A&OV.

## Researchers note: Shannyn and Gail



Shannyn Meloncelli



Dr Gail Crimmins

I (Shannyn) was diagnosed with RA when I was 36 weeks pregnant with my first daughter in September 2009. With a background in journalism I immediately went into research mode. Not long after my RA journey began Arthritis Australia and the Australian Rheumatology Association produced *Women's Insights into Rheumatoid Arthritis*<sup>9</sup>. Women with RA discussed their symptoms, pain and peoples' lack of understanding of the impact of RA. The publication touched on positive life strategies but did not go into in-depth detail. I wanted to know more about day-to-day coping strategies. The publication demonstrated how little is known about women with RA. Additionally, it outlined another gap - how little is known about how women and mothers cope day to day.

Eighteen months later I had another baby and was now a sole parent. Strategies to manage with pain and fatigue when rest wasn't an option, were vital. I became active on social media and began to share helpful advice with other mothers on their parenting journey. I was motivated to explore this process and share mothers' stories through research.

I met Dr Gail Crimmins during a three minute thesis competition at USC in 2013. We decided Gail's abilities to represent women's' stories in a truthful and accessible way could enable a productive collaboration into the future. In 2014/2015 this became a reality as together we embarked on a project to give mothers with RA a voice.

We now wish to use the lived experience and coping strategies of mothers with RA (their voice) to inform further research and to promote the possibility of mothers with RA supporting other mothers with RA; a strategy designed to empower both sets of mothers.

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## **Explore and document coping strategies and support mechanisms employed by mothers with rheumatoid arthritis (RA). (S/13/501)**

### **Research Team**

Shannyn Meloncelli (Masters student), Gail Crimmins and Prof Marion Gray (Student supervisor)

### **Background**

The aim of the research is to identify and record practical coping and support strategies employed by RA mothers and to give them a voice. The investigation, in particular, seeks to capture and re-present the resourcefulness of mothers with RA and demonstrate how they undertake specific parental responsibilities such as feeding and changing their babies. In addition, the project seeks to identify, acknowledge and share the practical strategies that mothers with RA devise and employ in order to carry out their domestic chores and responsibilities. The participants will volunteer to be involved in the project, in response to a local new item presented on Sunshine Coast FM (a local radio station). The participants of this study will be filmed whilst they carry out specific parenting and domestic tasks and will discuss to camera their practical management strategies and their rationale. The films will be available to the general public through youtube and possibly other support organisations so that they can be used as a practical resource for other mothers with RA.

All participants will be provided with this Research Participant Information Sheet prior to the commencement of the interviews and will discuss the specific filming process with the project researchers. Participants will have access to film recordings before they are made public and will have the opportunity to withdraw any sections of film, or full films' recordings, before they are made public. They will not need to offer a reason for withdrawing any footage from the public domain.

### **Research Significance and Purpose**

Currently there is limited research that explores the coping and management strategies that mothers with RA create and employ. There is also a paucity of practical guidance as to how mothers with RA undertake parenting and domestic responsibilities.

Through discussions on closed Facebook sites with RA mothers and other members it appears there is also a lack of understanding of RA mothers' lived experiences and performed practice. The intention of the research is to fill a gap in knowledge and to inform allied health professional practice and be of significant practical and emotional value to mothers with RA.

Newly diagnosed mothers have limited supportive literature outlining positive disease management and coping strategies. In particular, the research aims to inform and educate newly diagnosed mothers.

The research aims to document RA mothers' experiences focusing on positive personal attributes such as resilience, coping, supportive relationships and life focus/sense of purpose, and how these attributes affect management of the issues associated with having RA. The project specifically aims to:

Explore, demonstrate and describe resilience sources, coping strategies and support systems available for mothers with RA.

Inform allied health professionals such as Rheumatologists, Occupational Therapists and GP's of the lived experiences of RA mothers and the support strategies that they have devised to manage parenting and domestic responsibilities alongside managing the symptoms of RA.

### **Participant Experience**

Participation in this study is voluntary and participants may withdraw at any stage, without explanation and there will be no consequences as a result. Participants may also withdraw the clips even after they have been made available through youtube and support organisations.

Prior to the filming process participants will be sent a demographic survey to complete, which also contains questions that relate to health issues.

The filming will take place in the women's homes at a time and date convenient to them. Participants can choose to have a supportive person to be present during the filming process.

Mothers will be recruited through radio interviews describing the project.

Practical parenting and housework demonstrations will be video-recorded with the option for participants to offer a discussion/interview to camera based on their practical coping and management practice.

### **Duration**

Participants will be invited to volunteer approximately 2-4 hours once only. This time will be negotiable depending on the current wellness and availability of participants.

### **Risks**

This research study has been identified as low risk. However, as a participant with health issues it is important to be aware of a need to cease filming or withdraw from the research at any time without penalty or the need of explanation.

Sensitive information about health issues will be requested in the initial survey. However, in the filming process participants will be asked to discuss and demonstrate only positive coping and management strategies that they have developed as a result of living with RA. It is likely that some participants will find this produces some discomfort.

Participants who experience negative emotional issues as a result of participating in this research are encouraged to discuss them with the researcher themselves. If participants do not feel comfortable with this option, BeyondBlue operates an anonymous phone counselling service 24 hours a day 7 days a week (1300 22 46 36) or by joining their online forums via [www.beyondblue.org.au/get-involved](http://www.beyondblue.org.au/get-involved)

### **Results**

Once the films have been viewed and accepted by the participants, the film clips will be uploaded into the public domain via youtube. The findings will be used to acknowledge the lived experience and resilience of mothers with RA and to educate other mothers with RA

how they may undertake certain parenting and domestic responsibilities. They will be used to establish how RA mothers cope and how they employ support mechanisms to manage a chronic illness while also caring for a family and home.

These findings will also be used to write a research thesis and are intended to be submitted to Qualitative Health Research online journals for the viewing of allied health professionals.

Information may also be shared at conferences for medical professionals such as Rheumatologists.

Participants will have access to the film clips following their demonstrations and discussions allowing for changes to be made if participants feel their responses were inaccurately recorded. A one to two page summary outlining findings will be provided to participants following the completion of the research. Research information and transcriptions will be forwarded to participants via their designated email address or through written mail. Follow up phone calls, with the consent of the participants, will be conducted throughout the research.

### **Online Surveys**

The clips in the initial pilot phase of the research will be hosted on Arthritis Victoria's website. In order to ascertain the effectiveness of these clips in helping to educate women and families with RA a survey will be posted on the website in the weeks following the uploading of the clips. The purpose of this survey is to use the information to inform the filming and production of the main research project, the second phase.

### **Confidentiality**

Data gathered during the study does not identify you as a participant in order to acknowledge your resilience and coping strategies. You will be identified through the film clips on youtube, and available to associations that support persons with RA. You can request to not have your name published. The information will also be used to inform future PhD studies of Shannyn Meloncelli.

### **Complaints**

If you have any complaints about the way this research project is being conducted you can raise them with the Principal Researcher (Shannyn Meloncelli [slm028@student.usc.edu.au](mailto:slm028@student.usc.edu.au)) or Gail Crimmins ([fgcrimmin@usc.edu.au](mailto:fgcrimmin@usc.edu.au)), if you prefer an independent person, contact the Chairperson of the Human Research Ethics Committee at the University of the Sunshine Coast: (c/- the Research Ethics Officer, Office of Research, University of the Sunshine Coast, Maroochydore DC 4558; telephone (07) 5459 4574; email [humanethics@usc.edu.au](mailto:humanethics@usc.edu.au)).

*The Researchers and the University would like to thank you for your interest in this project and appreciate the effort involved.*



## CONSENT TO PARTICIPATE IN RESEARCH

### **Explore and document coping strategies and support mechanisms employed by mothers with rheumatoid arthritis (RA). (S/13/501)**

I have read, understood and kept a copy of the Research Project Information Sheet for the above research project.

I realise that this research project will be carried out as described in the Research Project Information Sheet.

Any questions I have about this research project and my participation in it have been answered to my satisfaction.

I agree to participate in the research project *researching the coping and support mechanisms of mothers with RA*.

I give consent for data about my participation to be used for the purposes of this research project, and in future research projects.

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*Participant*

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*Date*

# Arthritis

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