

An exploration of raising a child in New Zealand with severe allergies and the potential for an anaphylactic reaction.

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of the requirements of the degree of  
Master of Nursing  
at the  
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## **Originality Declaration**

I declare that the work presented in this research thesis titled “An exploration of raising a child in New Zealand with severe allergies and the potential for an anaphylactic reaction” is, to the best of my knowledge and belief, original and my own work, except as acknowledged in the text and reference pages.

Signed:

Date: 13.05.14

## **Abstract**

### **Introduction**

Both international and national research concludes that allergies within children are increasing, as is the severity of the allergic response (Allergy New Zealand, 2012b. Lauritzen, 2004). Some research suggests a sevenfold increase in allergy diagnosis within the past ten years however as both severe and mild allergic responses are often misdiagnosed it is difficult to know what the true increase is (Paweanker, Walter, Canonica, Holgate & Lockey, 2011-2012). This has led to fragmented responses from the medical profession. A lack of knowledge about the cause of allergies alongside how to best manage them has contributed to feelings of frustration in those who live with allergies and their caregivers. This research is an exploration of the experience of raising a child in New Zealand with severe allergies and the potential for an anaphylactic reaction. It focuses on the impact on the family when a child is diagnosed with severe allergies.

### **Aims of the research**

The aim of this research is to explore what is it like when your child is diagnosed with a severe allergy and the impact that can have on the whole family. Through the use of a personal narrative the research engages with issues concerning childhood allergies and encourage further conversations about allergy management. By increasing people's knowledge about the impact on families and encouraging further investigation this research hopes to encourage the medical profession to provide more consistent and responsive care for families living with allergies.

### **Methodology**

A qualitative method, autoethnography, was used as the aim of this research was to discuss the lived personal experience. As I am the mother of a child with severe allergies and the potential for an anaphylactic reaction, as well a nurse who is undertaking the research, I am in a prime position to inform people about the intricacies of living with allergies. This required a methodology that allowed for the lived experience to form the basis of the research.

Through the use of autoethnography I have been able to take readers through a journey of an aspect of my life, using my story to both inform and educate. Gibbs' (1988) model of

reflection was utilised to assist with the analysis of my narrative, and pseudonym names were used to assist in ensuring privacy.

### **Findings**

Several themes emerged. These were discussed under the subheadings: The mother, The nurse, Who is supporting us, and Desperately seeking knowledge. 'The mother' discusses the emotional response and how the diagnosis affected me and my ability to cope. Under the subheading 'The nurse' I identify a role conflict between being both a mother and a nurse employed at the hospital where we sought care for our child. The lines blurred creating a gap between both the care we sought and the care offered. The question 'Who is supporting us' I asked who is supporting us as a family, who is supporting my child as she grows, goes to school and engages in the wider community and who is supporting me to care for her? Finally, 'Desperately seeking knowledge' discussed my desire for knowledge and the various sources I utilised to get answers to the questions I have about allergies.

### **Conclusion**

The goal of this research was to better inform nursing practice. This deeply personal and reflective insight into raising a child with severe allergies has highlighted the potential for nurses to play a major role in assisting families as they come to terms with an allergy diagnosis. There is an opportunity for nurses to establish an allergy care pathway. A pathway which would assist both the family as they learn to live with allergies and integrate within a community, and also the child as they progress into autonomous care for their allergies.

## Acknowledgements

The body of work represents nearly 18 months of time consuming study which would not have been possible had it not been for the support and encouragement of many people. It is only fitting that I acknowledge their contribution.

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Finally I need to thank my family: Both sets of grandparents who continue to care for my children so I can study, work and socialise knowing they are in safe hands. My husband, who made my dreams come true the day I met him. His continued love and support encourages me to be the kind of mother I want to be, and finally my children. Their laughter brightens even the greyest day and their snuggles fill me with resounding comfort. It is for them that I write this.

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## Chapter 1

### Introduction

Becoming a parent is a life altering event. Whilst it has enhanced my life beyond my greatest expectations, I have also found that the image I had in my head of how my life would be when I became a mother quickly changed in front of me. As a child I played with dolls, pretending to be mum. In my teenage years I often babysat children, there too I was taking on the persona of a parent and envisaging what it would be like when I had my own children. I met my husband when I was 20 years old, and even early in our relationship I fantasised about having children and life as a family. However it was not to be how the advertisements on television or movies portrayed family life. In some ways I felt set up to fail because I could not live up to this image that I, scaffolded by the media, had built up in my head. These feelings were exacerbated when my precious baby girl suffered her first severe allergic reaction which resulted in a long list of foods that were potentially life threatening for her. The so called 'normal life' raising a 'normal child' morphed into one of constant supervision and fear.

I chose to undertake research into the management of children's allergies within New Zealand because I am the mother of a child with severe allergies with the potential for an anaphylactic reaction. I am deeply concerned about allergy management because I have lived it and feared it for the past four years. However I was at a loss as to how to best to undertake research about what it is like to be the parent of a child with severe allergies. I wanted to share my story about how our family has coped with allergies. Through the use of pseudonyms, I will introduce my family and take the reader on a journey through our lives detailing how allergies have impacted on us.

I often relive moments in my life with Nancy, questioning how I introduced Nancy to solids, asking myself if I impacted on her development of allergies. There are a barrage of questions I found and still find myself asking. Could I have breast fed for longer? Would my marriage survive if something happened to Nancy which vigilant care could have avoided? Could I live if an allergic reaction cost me Nancy? What can I do to avoid this and how will I manage a reaction if Nancy is exposed to allergens again? When has minimising risk gone too far, where do you draw the line? Am I wrapping her in cotton wool? Who do I listen to?



Whose advice to value and follow? Did this advice contribute in some way to the situation I found myself in? Am I a good parent? Am I a good mother?

In this research I have utilised an autoethnographic methodology which allows me to use my personal narrative to detail these experiences and how Nancy's allergies has shaped our lives to what they are today. I have utilised Gibbs' (1988) reflective cycle model to separate these experiences and corresponding feelings into manageable segments, and reflect on these to make sense of my emotional responses in order to provide a deeper honesty in my story.

I read an article in a women's magazine where Alecia Moore (also known as Pink) had been interviewed. She discussed how "mum fear is a different kind of fear – It's all-encompassing. You just want to make sure that no matter what happens in the world, everything is taken care of" (Brodeser-Akner, 2010. P.87). This resonated with me for two reasons, firstly here was this female role model whom I looked up to talking about how hard and scary motherhood can be. This made such a nice change as I feared I was the only one who struggled with it from time to time. Secondly, this woman had unlimited finances at her disposal and a child without chronic conditions, I felt like I could say, 'well if you find that difficult, imagine doing it on a middle-class income and adding life threatening allergies to the mix.'

I don't want to sound like I think I have it harder than everyone else. I know how lucky I am to have a happy little girl who for the most part, is healthy. But living with this all-consuming fear on top of those held by all parents is where I struggle. For me it is a balancing act between being a relaxed happy mum, and being an overprotective fretful mum who is conscious of every piece of food or every animal that goes anywhere near her child.

There have been very few published New Zealand studies focusing on the experience of being a parent of a child with severe allergies. The intention of this study is to detail a journey identifying common themes and then analyse these using Gibbs' (1988) model of reflection.

Gibbs' (1988) reflective cycle (see Appendix A) is used in nursing practice to help the reflective practitioner to make sense of experiences and examine their practice. However reflection itself is not enough as it also needs to inform future practice (Gibbs', 1988). Through the use of this model I reflect on my experiences with Nancy and her allergies with a view of informing myself and my readers. I have used it to reflect on specific moments in our life.

### **Structure of the thesis**

This thesis is presented in six chapters. The first chapter introduces the topic of the thesis and how this has been addressed.

Chapter 2 provides a broad overview of the relevant research and literature around the areas of allergies and allergy management. The literature review is structured around subheadings which identify how allergies are defined, the incidence of allergies within New Zealand and internationally, the impact on a family of having a child with medically diagnosed severe allergies, and how allergies are managed within the medical field, communities and within families.

Chapter 3 explains the method and methodology. This is a qualitative autoethnographic study which utilises my story of raising a child with severe allergies as the data to inform and analyse. Justification for this method alongside ethical considerations and information about how this data will be analysed is included within this chapter.

Chapter 4 is written in the form of a narrative. It is here that key characters are introduced. This includes myself, my husband, my son, extended family and Nancy – my daughter who has medically diagnosed severe allergies and is the catalyst for this research. Within this chapter I discuss pregnancy and birth, life up to Nancy's first allergic reaction, diagnosis of the allergies, its subsequent impact on my life and that of my families, how we are learning to manage her allergies, as well as how we have learnt to trust in other extended family to help care for Nancy.

Chapter 5 discusses and reflects on the narrative. Gibbs' (1988) model of reflection is utilised to assist with this analysis. Major themes from within the narrative are identified and summarised.

Chapter 6 concludes the research, identifying some of its limitations alongside recommendations that this research has produced. Implications for further research are discussed alongside how this could inform and alter future nursing practice. Within this chapter Nancy has a voice and opportunity to discuss how having an allergy has impacted on her. This chapter concludes with an epilogue detailing the current situation with regards to Nancy's allergies as well how this research has altered our lives.

## **Chapter 2**

### **Literature Review**

#### **Introduction**

Johnson and Webber (2005) suggest that a relevant and thorough literature review serves to advance knowledge by identifying not only what is known but also what is unknown about a particular phenomenon. When I began my literature search on allergies in children I was surprised by what my searches produced. Whilst there is a considerable literature base within the field of allergies in children, as I refined my searches it became more difficult to find relevant, peer reviewed literature published within New Zealand or Australia. Allergies are becoming more frequently reported in main stream media with many reports garnering public attention. However within New Zealand allergies and allergy management have not been widely researched. My searches confirmed that this is a topic about which there is a great deal to learn.

An adequate literature review takes the breadth and depth of published works and breaks it down into small usable pieces (Burns & Grove, 2009). An important factor I had to consider when reviewing literature was how the studies had been conducted. For example: Were the studies I was reading addressing adults or children with allergies? Were they dealing with a self-reported allergy or a medically diagnosed allergy? What was the nature of the allergy? Was it a food or an environmental allergy and what was the body's response? Was the difference between a food allergy or food intolerance understood? Were these studies looking at the physiological or psycho-social impact of allergies?

Through the use of online library databases, mainstream media and blog cites, alongside articles, that I had saved because of my ongoing interest in allergies I gathered my data. Within my literature searches there were some recurring themes which focused my literature review. For example: What defines an allergy? What is the incidence of allergies within New Zealand and other western countries? Why are allergy diagnoses on the rise? Finally what is the impact on both the children with the allergies and their families and how these allergies are managed or treated?

A report published by Allergy New Zealand (2012) notes that there have been very few studies produced in New Zealand that look at food allergies. This is in line with my findings,

I struggled to find many relevant articles on allergies in children, especially ones that focussed on the impact on the whole family. Due to a lack of New Zealand and Australian literature on these topics I also looked further afield. I did however restrict myself to mostly western countries so that diet and treatment options would be similar. This comes with the added benefit of comparing allergy prevalence and management with other countries. My key terms/words used when accessing online library databases, consisted of 'allergy' or 'hypersensitivity' and my associated words were 'children' and 'parents'.

### **What defines an allergy?**

Braun and Anderson (2011) define allergies as an excessive response to an allergen. The response to these allergens is inappropriate ranging from mild to severe and can become life threatening. Potential allergens can be found everywhere in everyday life and include both environmental allergens such as dust or pollen and allergens encountered in food products or drugs (Braun & Anderson, 2011). When discussing allergic reactions to food and drugs it is important to recognise that it is the food proteins that activate the immunological response causing a cascade of clinical symptoms and that these proteins can be altered through cooking. For example this can mean that a reaction to cooked eggs may be different from a reaction to uncooked egg in mayonnaise, or from separated whites and yolk (Brantlee Broome-Stone, 2012).

Reactions to food can be classified as either an immunoglobulin E (IgE) or non-IgE mediated response. The IgE response accounts for those with life threatening allergic reactions (Brantlee Broome-Stone, 2012). Anaphylactic allergic reactions can be further defined as an extremely serious or immediate response, and are characterised by oedema and vasodilation leading to hypotension. The progressions of anaphylactic reactions are life threatening (Braun & Anderson, 2011). An anaphylactic reaction can begin within seconds of exposure to an antigen to which a child has been previously sensitised and is a result of the IgE mediated allergic response (Brantlee Broome-Stone, 2012).

A food allergy is not the same as food intolerance, such as intolerances to gluten or lactose. Edwards, George and McQuaid (2010) differentiate these reactions, stating that an allergic reaction is an abnormal, immunological response to food proteins. Food intolerance will not activate the body's immune system and is not considered life threatening.

Exposure to an allergen can affect one or multiple body systems. The resulting myriad of clinical symptoms can involve the integumentary system, gastrointestinal tract, and respiratory tract (Brantlee Broome-Stone, 2012). Allergies often share co-morbidities such as asthma, eczema and rhinitis with or without conjunctivitis, with children often experiencing two or more of these or exacerbated co-morbidities (Galloway, 2012). The most common triggers for an allergic reaction in children include peanuts and tree nuts, milk, egg and drugs (more common in adults). A small number of children will react to venom such as stinging insects. The response to these allergens is unpredictable and can range in severity. Typical responses include:

- Pruritus
- Urticaria
- Angio-oedema, especially of the face or larynx leading to dyspnoea and dysphagia
- Abdominal cramps
- Nausea
- Asthma progressing to severe asthma
- Collapse and unconsciousness

(Galloway, 2012).

### **Incidences of allergies**

Lauritzen (2004) carried out research into the sudden rise in allergies where she described allergies as “a disease of our time” (p.1299). Estimating that in Sweden where this research was carried out allergies were thought to effect approximately 40% of children. New Zealand is lacking in statistical information related to allergies. There has been no hard data collected and collated which give a true reflection of the amount of people living with allergies. I believe this is in part due to large amounts of anecdotal evidence. The variety of allergies and allergic responses make it even more difficult to collect and collate information; therefore it is necessary to make comparisons with other countries similar to New Zealand with regards to diet and health care.

Allergy New Zealand (2012b) notes that not only are allergies increasing in prevalence but the allergic response is becoming more complex and serious. However in a separate report Allergy New Zealand (2012a) also claim that the actual prevalence of allergies is difficult to ascertain. Partially because there is no collected statistical information about allergies in New Zealand and also because of confusion about what defines an allergy. The report goes

on to say that many international studies indicate a marked increase in allergy prevalence but that it was hard to draw specific conclusions, citing that in some studies people had self-diagnosed their allergies and others were doctor diagnosed. When the self-diagnosed allergies were excluded the rate of people who answered “yes” to having an allergy could drop from 38% to anywhere between 1 and 11% (Allergy New Zealand, 2012a. p. 1). This was the only published report that identified the theory that the incidence of allergies was increasing. Most international and national agreed that allergies were increasing substantially and required more funding and research. Further documents released from Allergy New Zealand appeared to share this belief. Allergy New Zealand (2012b) has made identifying and quantifying the prevalence and impact of allergies in New Zealand one of its priorities and is currently undertaking research in this area with a hope of publishing credible research over 2013-2014.

Paweanker et al. (2011-2012) state, “The prevalence of allergic diseases is increasing dramatically...this is especially problematic for children who bear the greatest burden of this trend” (p.1). The report goes on to say that despite a worldwide increase in allergies and allergy complexity, the health services available remain fragmented and far from ideal, stating “very few countries have comprehensive services in this field of medicine” (Paweanker et al, 2011-2012. p.1). Allergy New Zealand (2012b) appears to concur with this statement citing Dr Jan Sinclair, Paediatric Clinical Immunology and Allergy Specialist at Starship Children’s Hospital in Auckland. She believes that due to the recent dramatic rise in allergies and their severity, many centres throughout New Zealand are ill-equipped to appropriately manage allergies (p.8).

Galloway (2005) suggests that allergies affect nearly 40% of children within the United Kingdom. This statistic includes allergies that produce an immediate reaction and more subtle allergic reactions which lead to diarrhoea, reflux, poor weight gain and eczema. Although those are not immediately life threatening they are difficult to diagnose and often lead to increased feelings of frustration and heightened stress for parents. McBride, McBride-Henry and van Wissen (2010) concur, noting a significant rise in occurrences of allergies in children within Western countries. Dunbar and Luyt (2011) cited studies which showed a sevenfold increase of anaphylactic reactions in the United Kingdom but go on to highlight that the true number of anaphylactic reactions is uncertain as it is difficult to distinguish anaphylaxis from lesser reactions making the true prevalence difficult to

ascertain. From another study based in Melbourne Australia, Dunbar and Lyut (2011) state the median age of children's first reaction is two and a half years.

The American Food and Drug Administration (FDA), (2012) report that allergies have increased over the last ten years. Food allergies now affect two percent of all adults and eight percent of children and those children are less likely to grow out of their allergies (FDA, 2012. p.37). The FDA also states that children with food allergies are more likely to have asthma, eczema, and other types of allergies. This finding is in line with research conducted by McBride et al. (2010), and the aforementioned research conducted by Galloway (2012). The FDA further report that 30,000 Americans required emergency room treatment, and 150 Americans die each year because of allergic reactions to food (p.37). There are no statistics provided on either the New Zealand Ministry of Health website nor Statistics New Zealand for the number of New Zealanders who required treatment for allergic reactions from tertiary health care providers, or if there have been any fatalities.

Both Brantlee Broome-Stone (2012) and Sohi and Warner (2008) discuss their separate research as to why allergy prevalence is increasing. Both pieces of research theorise that genetics and environmental factors play an important role. A child is more likely to have an allergy if he/she has a parent or sibling with an allergy. Both pieces of research also cite changes to our diet and lifestyle over the last five decades and the hygiene hypothesis as potential causes for the increase in allergy rates. Bennett (2004) also attributes the rise in food allergies to the processing which modifies the molecular properties of food allergens.

The hygiene hypothesis explores the possibility that living in a time where there is an increased emphasis on hygiene, coupled with smaller family sizes, is inhibiting the human body's ability to create an effective level of resistance. The fact the allergies are more prevalent in first born children is cited as one reason why this could be a credible hypothesis. It is believed that the first born child will bring dirt and bacteria to the second born child, even in the most hygienic homes, assisting to increase the second child's immunity (Brantlee Broome-Stone, 2012; Sohi & Warner, 2008).

### **Impact of allergies**

Mc Bride et al. (2010) produced the first piece of published New Zealand research which examined the impact on parents and family and their experience of parenting a child with



Medically Diagnosed Severe Food Allergies (MDSFA). Three major themes were evident within their research: the experience of isolation, the burden of accessing resources, and the cost of living with MDSFA. The researchers also recommended that families were supplied with education to meet the developmental stages of the child/children with MDSFA. They further identified a need for families to have multi-disciplinary support and a requirement to review the provision of education for children living with MDSFA. They concluded that New Zealand fell behind other Western countries with regards to the amount of support offered to families and communities to assist in managing MDSFA. The research by McBride et al. (2010) produced a number of recommendations which included; further research, greater governmental funding and consistency for allergy management within the New Zealand district health boards and schools. Whilst their findings are valuable it is worth noting that all of the participating parents in this piece of research were married, of European decent, professional couples, living in the North Island. The research by Mc Bride et al. (2010) reflects a small sector of New Zealand society. All four participants could afford private medical care for their children and auto-injectors for potential anaphylactic reactions. All four mothers had chosen to, and could afford to, provide full time childcare at home and not be in paid employment. Being in the North Island also gave these families easier access to immunologists and specialist care which is often difficult to access in the South Island especially since the only South Island based immunologist relocated to the North Island in the years after the Christchurch earthquakes. It can be assumed that these factors would allow the research participants greater access to more health care services, through both the private and public systems which may not be necessarily available to families outside the noted demographic.

Brantlee Broome-Stone (2012) discussed an increasing need for health professionals to understand the “psycho-social impact of allergies on families” (p.1) and not just to focus on the biomedical impact. Kim, Sinacore and Pongracic (2005) acknowledge that the quality of life for this population is diminished. They suggest that this psychological component coupled with knowledge deficiencies as contributing to the under use of adrenaline auto-injectors (Kim et al., 2005). In line with this study Williams, Parra and Elkin (2009) evaluated the emotional functioning of parents of children with food allergy. Their findings are similar to that of Mc Bride et al. (2010) who concluded that parents or caregivers experience the same increased feelings of emotional distress, coupled with increased guilt and worry, uncertainty and sorrow, when compared with parents of children with chronic

illness. Williams et al. (2009) suggest that the increased feelings of frustration and stress for the parents are related to the lack of appreciation for the seriousness of the allergy from both the community and health sectors, sadness about the impact of the allergy on the child and worry about the child's ability to lead a normal life.

Children have also expressed increased feelings of frustration imposed by allergies on their regular activities and normal life. Stewart, Masuda, Letourneau, Anderson, and McGhan (2011) noted children's common complaints included their inability to have a pet, worry about an allergy exposure, managing medications and embarrassment about restrictions on food whilst with their peers. They also described negative impacts on the activities of daily living and quality of life. This study highlighted that children with allergies regarded asthma as more controllable than allergies and that children with both asthma and/or allergies often felt they had to hide it from their peers out of fear of harassment. One child in the study talked about being bullied about her allergies and felt her peers did not take it seriously. All of the children interviewed for this study discussed a desire to have some form of peer support.

### **Managing and treating allergies**

Paweanker et al. (2011-2012) believes that because of the dramatic increase in allergies worldwide, allergy should be regarded as a major healthcare problem. The management and treatment of allergies in New Zealand is of increasing concern, with most international and national literature concurring that because allergy prevalence is increasing and allergic responses becoming more severe, there needs to be an emphasis on how allergies are managed and treated. The New Zealand Herald reported on the coroner's findings after the death of an eight year old boy following an anaphylactic reaction to a cashew nut. Within their article they cited the coroner who stated that similar deaths could be avoided if Adrenaline Auto-injectors were readily available (Leask, 2009). During 2011-2012, Allergy New Zealand commissioned Dr Marianne Epson, a Clinical Immunologist to gather evidence and with her support, Allergy New Zealand made a strong case to Pharmac to have adrenaline auto-injectors funded. Whilst this decision is still under review by Pharmac, Allergy New Zealand states that this will be an on-going campaign (Allergy New Zealand, 2012b).

Allergy New Zealand believe that the fragmented health services leave people feeling isolated and alone with regards to the management of their allergies. They cite the expense of adrenaline auto-injectors as the main reason why people may not have one, even though they believe that adrenaline auto-injectors can make the difference between life and death. The inability to afford adrenaline auto-injectors has led to people looking to the internet and other sources to find help. Allergy New Zealand caution how this can lead to people trying unproven and sometimes unsafe treatments. In their 2011-2012 report they discuss advocacy roles they have undertaken where they have successfully taken a case of this nature to the Commerce Commission (Allergy New Zealand, 2012b). Paweanker et al. (2011-2012) also discuss how people seek non-scientific diagnoses and remedies for their ailments due to a lack of direction and care from health services. This includes complementary and alternative therapies. Allergy New Zealand (2012b) go on to discuss the avoidable mortalities and morbidities due to a lack of allergy management.

With food and environmental allergies becoming more prevalent there is a need for consistency and regulation within how they are managed. Kim et al. (2005) believe that parents are ill-prepared to manage their child's allergy's noting that in a telephone survey of children attending a specialist allergy service only 29% of recurrent anaphylaxis was treated appropriately with an Adrenaline auto-injector. They believed that parents were deficient in their knowledge about symptoms of anaphylaxis alongside knowledge about how to use their device. This is especially important when you are discussing allergies in children. If parents are struggling with identifying when and how to treat anaphylaxis a question needs to be asked about how we teach children to manage their allergies and at what age is it appropriate that they will take over the responsibility for their allergies from their parents or caregivers. Inconsistency with the information they are given adds to the increased feelings of frustration for the child, but is thought to also cause a decline in their management and treatment compliance (Stewart et al. 2011).

This literature review has not only highlighted many of the same frustrations and fears I am continuing to experience, but it has shown that these emotions are not isolated to just myself and my family, but instead experienced both nationally and internationally. One of the main themes when reviewing the large amounts of published literature was inconsistency in information regarding allergies and the management of them. It would appear that internationally we are in agreement that allergies are increasing in both

prevalence and severity, however both health and community sectors appear to be failing to recognise the increasing needs of the people with allergies and their families. I believe that there is a need for continuing research into allergies in general in order to enact change and increase public awareness of the daily challenge of living with allergies.

### **Summary**

The literature review identified that nationally and internationally, the reporting of allergies and MDFSA is becoming more prevalent. However the literature shows that there remains uncertainty as to the causes of this increase. This has led to inconsistencies about how to best manage children with allergies and what the future impact of allergies will be. My review highlighted a lack of material about how parents are coping with their child's/children's allergies. This pre-empted the course my research would take through detailing how parents in New Zealand are living with their child's allergies.

## Chapter 3

### Methodology

#### Introduction

This chapter describes and discusses the methodology selected for this research. It justifies and provides rationale for the chosen method, and details the merit of this method within nursing research.

Medical and nursing initiatives are expanding and changing at a rapid pace meaning that reading research is a part of life now for all nurses. A need to stay abreast of the latest information and research is imperative, not only in a nurse's particular area of practice but also in nursing generally. However this can be a monotonous task for some nurses. I often struggled with reading research, finding myself planning shopping lists or what I was going to cook for tea before re-orientating myself to the task at hand which was reading the latest nursing publications. This is not to say that what I read was not interesting; more that I could not relate to the style of writing. Reading research is something I really had to work at. This has led me to look at different styles of research and writing and to carefully consider which would be the most appropriate method for my own research.

After the diagnosis of Nancy's allergies there was a change in the dynamics of our family. The full impact of her diagnosis came with a realisation that our lives were not going to be as straightforward as we had thought. The very nature of this realisation and the journey it sent me on was the basis for undertaking this study. I had a desire to increase people's knowledge about allergies, the impact of allergies and how we could better manage them. This required an expressive narrative methodology that allows for the unique personal context in which I approached the topic. My journey into methodology literature has opened my eyes to a world of possibilities and directed me towards a qualitative autoethnographic study.

My goal, through using this style of writing is that my story will convey knowledge from a personal perspective and be a catalyst for more conversations about severe allergies in children. Lauritzen (2004) identifies that knowledge about health and well-being expressed from the perspective of the individual experiencing it, should not be viewed as different or inferior to medical knowledge but rather as complementary. Providing an everyday

context and answering different questions (Lauritzen, 2004). The benefit of this type of methodology is that it allows me to provide both the medical perspective as well as the perspective of the individual experiencing the alteration in health status.

Ellingson and Ellis (2008) draw a distinction between two types of autoethnographic research. They suggest that “analytic autoethnographers focus on developing theoretical explanations of broader social phenomena, whereas evocative autoethnographers focus on narrative presentations that open up conversations and evoke emotional responses” (p. 445). This thesis lends itself to evocative autoethnography as it details the events of my life, inviting readers to undertake our journey through some of the key events in our lives with a goal of evoking an emotional understanding within the readers.

As with most narratives, the story told in this autoethnography will be on-going, but for the purposes of this research the story describes the time from Nancy’s birth until the commencement of this thesis in May, 2013. I decided to put a final date on it for fear of it becoming a never ending task.

This type of qualitative research sits within an interpretive paradigm in which there may be many truths and multiple realities. Human beings are too complex to be captured by a one dimensional positivist methodology (Maykut & Morehouse, 2000). Through the use of this paradigm I aimed to increase understanding of the human condition my family lives with, avoiding the necessary generalising of quantitative paradigms (Maykut & Morehouse, 2000). Beanland, Schneider, LoBiondo-Wood and Haber (1999) discuss qualitative research and how it can encompass a holistic view of the research. My realities of the experience my family went through will continue to be a holistic perspective of our environment. An interpretive paradigm within qualitative research will allow my story to remain focused whilst being broad and open ended.

### **A qualitative methodology**

Strict guidelines usually govern how nursing research is conducted and written. As a nurse educator I instruct my students to write in an uninvolved voice, devoid of emotion and to refrain from making “I” statements, encouraging them to stick to the facts. Ellis (1997) believes that this is a consequence of losing faith in our “theory of language” (p.115). She questions why it is more valuable to study groups of people through the use of surveys,

interviews or questionnaires, instead of building on our own experiences. Ellis (1997) reflects on her own work, referring back to a project she researched on jealousy. She noted that her work would have been enhanced had she been able to refer to her own experiences of jealousy and how her emotional responses influenced what she saw and wrote (p.124). This would have allowed her to build on the physical and emotional responses, the “raw emotion” that she found was lacking in the surveys she had distributed. In effect, Ellis (1997) seems to yearn for the richness of information that comes from research within the qualitative paradigm and requirements to reflect on it.

Qualitative research is used in nursing to enhance the understanding of human health by combining both the artistic and scientific nature of nursing, attempting to make sense of phenomena by studying subjects in their own environment (Beanland, Schneider, LoBiondo-Wood, & Haber 1999). I have always been drawn to this style of research and knew I would want to use a qualitative methodology for my own research but I then had to determine the most suitable design to use under the qualitative umbrella. An autoethnographic design allows the writer to connect the reader directly through the use of the author’s own story, allowing the reader to picture themselves in the research and react emotionally to what was written (Ellis, 1997). This gives the author the potential to further enhance the reader’s understanding of human health by allowing them to vicariously live the experiences of the author.

### **Autoethnography**

Autoethnography is a method that allows the reader to connect to the writer through the use of an evocative and descriptive narrative (Foster, McAllister & O’ Brien, 2006). The aim of autoethnographic research is to increase cognitive awareness by stimulating emotional and spiritual reactions (Ellis, 1997). For me, reading an article written in this narrative was like picking up a novel. I could relate to the experiences of the writer because of how they described their personal reactions and I felt connected to them. This response meant that I was better able to recall what I had just read because I felt part of it. This is what I wanted for my own research. I want my readers to connect with me through my story and for my story to become the basis for a continued interest in allergy management. My hope is that, after reading my story, readers will want to find out more about allergies and allergy management.

Research utilising autoethnography within nursing is limited. This leads me to elaborate on the research produced by Foster et al. (2006). I believe that, along with autoethnography being relatively new to the research world, it is even newer within nursing research (Foster et al. 2006). Its form can take on different meanings in different disciplines. When I refer to autoethnography I am using the term as it is used in the social sciences, combining analysis and interpretation with narrative details (Change, 2008).

Hurwitz and Charon (2013) discuss a saturation of narrative knowledge within medicine. Although personal narratives have always been utilised and stories have been verbally passed on to new staff, it has only been in recent years that we are recognising the power of bringing story-based telling, appreciation of, and analysis into the routines of scientific clinical work. Autoethnography utilises this story-telling approach to produce writing that is drawn from both compassionate understanding and rigorous reflection. This method allows the researcher to be consumed with both the 'self' in the writing whilst remaining concerned with the broader context within which their experiences have occurred (Foster et al. 2006).

Patients now look to media-text, film, photography, fine arts, performance arts and other innovative ways to learn about, or convey, health and illness (Hurwitz and Charon, 2013). With this in mind, autoethnography can be seen as a bridge, connecting the culture or illness that is being studied with a reputable form of research which can be analysed and peer reviewed. Autoethnography ranges from an autobiographical study of one's own lived experience to studies where the researcher's experience is explored alongside others, through to stories where the researcher's experience of conducting the research becomes the actual focus of the research (Foster et al. 2006). This method differs slightly from autobiography which also uses one's experience and life story to inform and educate others. Whilst autobiography and autoethnography are similar, the main difference is the 'ethnos' within autoethnography. This is a desire to refer the story back to the wider community (Foster et al., 2006).

Autoethnography also differs from ethnographic studies. Austin and Hickey (2007) differentiate between the two methods by pointing out that "ethnography truth is externally verifiable whereas autoethnography has phenomenological constructions of truth in identity construction feature as a key point of the research process" (as cited in



Wijayatilake, (2012 p.107). Denzin (2008) differentiates between the two methods by highlighting that autoethnography does not adopt the objective outsider convention and accepts the individual in the research.

Denzin and Lincoln (2005) describe autoethnography as “setting a scene, telling a story, weaving intricate connections among life and art, experience and theory, evocation and explanation...and then letting go, hoping for readers who will bring the same careful attention to your words in the context of their own lives” (p.763). For me this means autoethnography will allow me to draw readers into my life, for them to feel my fear and frustration and for my readers to take these emotions and delve further into their meaning, learning and perhaps reading more about allergies and allergy management.

Readers of autoethnographic studies or literature may ask themselves what is the legitimacy and value of one person’s experience. Denzin and Lincoln (2005) implore scholars to ask themselves how much do they know, how do they know it and what they can do with this knowledge in the world? The truth is I know a lot about what it is like to raise a child with allergies in New Zealand. Therefore it can be viewed as my responsibility to disseminate this information. It may only be one person’s experience but I am in the unique situation where I am not just raising a child with severe allergies but I am also educated and experienced within the health field.

Autoethnography may allow the reader to picture how I am coping, then to ask themselves how they would cope if they were in my shoes. The hope is that this will lead them to ask how others manage in a similar situation (Ellis, 1997). My experiences will form the data that makes up my narrative. Through writing my narrative I hope to raise and extend peoples understanding of living with children with allergies. By writing in a style that differs from traditional formal writing, I intend to make knowledge more accessible.

In order to achieve the dissemination of further knowledge, careful planning needs to be done to determine the best format, structure and what information is worth sharing. Chang (2008) reminds me that this process is never neatly linear or sequential. Autoethnographic writing is multi-layered with narrative analysis and interpretation often happening concurrently with the narrative collection. This method does not follow a

conventional formula requiring the author to experiment with their own voices and structure (Kahn, 2011).

### **Generating, interpreting and analysing the narrative**

Chang (2008) states that, "Narrative analysis is at the centre of research endeavours, whether qualitative or quantitative research. Until you give meaningful structure to collected narrative they may appear to be a 'messy' pile of fragmented bits" (p.126). It is through the narrative analysis I can search for specific themes and relevant information, organising the 'messes' of collected narrative. Narrative analysis and interpretation are not synonymous with each other although they are not independent from each other either. Narrative interpretation will require me to decipher the cultural meaning from within my narrative story. Narrative analysis will ask why or how different experiences or reactions happened and/or the reverse of that, why didn't they happen or work (Chang, 2008).

A key advantage within this method is that being a mother of a pre-schooler consumes the majority of your thoughts and emotions every day. Being a mother of a child with severe allergies adds to that further by a constant need to be vigilant with the child's surroundings to ensure their safety at all times. All of this gives me a significant amount of information to draw on for my narrative and to analyse what is the most relevant themes to discuss. According to Gatefield (2010) there is far larger amount of varied and comprehensive information when compared with studies involving participants over a set period of time. There are no limitations such as population or time span and no risk that I, as the researcher, can misinterpret the experiences or emotions expressed by the participant being researched.

Chang (2008) highlights narrative analysis and interpretation as being difficult steps when beginning to write autoethnographic research. This is because they hang on the narrative collection and do not belong to a ridged research design. In order to write using this method there is a need to understand the fluidity of the process and to maintain flexibility when analysing and interpreting narrative (Chang, 2008). For my research to maintain its merit/accountability and not deviate within themes I was required to constantly reflect on what I thought I knew about my child, her allergies, being a nurse and a mother, and identifying my biases and the questions I am trying to answer (Kahn, 2011). I required the ability to let go of my inhibitions and freely write my narrative. I then needed to reread and

reflect on what I had written to ensure that my narrative stayed true to our experiences and ensure relevance to the research. I had not kept a reflective journal of our experiences until I began thinking about undertaking research about it, in December 2012, three years five months after Nancy's birth. I had kept her baby books with specific entries about her allergies and hospital visits. A reflective journal may have made the writing of my narrative much easier. The most logical way to proceed within my narrative writing is as evidence of my personal actions and thought processes, illustrating how Nancy's allergies and my perceived lack of external support influenced my life.

In order to fully relive my experiences and recapture how I was feeling with Nancy's allergy diagnosis hospitalisations and how her allergies impacted our daily life I have utilised structured reflection. Gibb's (1988) model of reflection, see Appendix A, encourages a clear description of the situation, analysis of feelings, evaluation of the experience, and analysis to make sense of the experience to examine what you would do if the situation arose again.

My narrative required multiple drafts and my thesis underwent major structural and content changes in organisation, format, voice and content. This enabled me to understand the relevance of each theme and how they related to the reader (Kahn, 2011). I was required to capture and write about different memories whilst also trying to capture the emotions felt at those specific times. The evolution of my writing illustrates the flexibility of qualitative research design (Chang, 2008). This does not mean that my writing is any less diligent nor does it refer to an indecisiveness in my planning, instead it highlights how qualitative research methods allow for freedom to modify plans as required in order to write an insightful understanding of human experiences (Chang, 2008).

Once my story and narrative was generated it was divided into separate themes within my lived experience; 1) Family history and Nancy's' birth, 2) Life up to first reaction, 3) Diagnosis and impact, 4) Management – day to day life and financial cost, 5) Caregivers and reliability – fear and isolation, 6) Allergy Phenomena – Experiences of my support group, 7) What I feel we need going into the future. This allows for further dissemination and analysis of how Nancy's allergies impacted and continues to impact on my family's life

Ellis (2004 p. 270) believes “we need research that reflects peoples’ lives not surveys and questionnaires that use irrelevant questions and dubious methods to test somebody’s research hypothesis” (as cited in Wijayatilake, 2012 p. 109). Denzin and Lincoln (2005) motivate writers using an autoethnographic method to move readers emotionally and toward concerted social, cultural, and political action. It will require more than me writing about my experiences for there to be a change in how allergy research is funded and therefore how we, as a country, manage allergies in our children but hopefully this will be a building block toward a notion of change.

### **Ethical considerations**

I am telling my own story from my own lived experience. This approach does not require New Zealand Ministry of Health, Health and Disability Ethics Committee approval. Approval for this research was gained through Eastern Institute of Technology Research and Ethics Approval Committee (Appendix 1). B

Autoethnography is most powerful when it is utilised to research or study something traumatic or otherwise paramount to the author’s life (Gatefield, 2010). This in itself opens up the possibility of causing undue harm by the very nature of the subject being written about. When undertaking this method of writing the author needs to do some internal self-discovery, and ask themselves, will remembering and reliving this experience cause undue harm to themselves as the author? Would the dissemination of this experience adversely affect the author either professionally or socially in any way? I asked myself these questions when deciding to share my story and although I cannot predict any harm coming to me through the sharing of my story it was something of which I remained mindful when choosing to share intimate details of my life.

It has been suggested by my colleagues that using an autoethnographic method will lessen the ethical issues for me as the narrative is my own story. However using my experiences could provide greater complexity as others would be unknowingly interwoven into my story. This meant there was the potential for profound consequences for the people who are written about. There is no way to predict how people will feel about being included in my research, even if informed consent is sought there is still a risk that they won’t be happy about what I as the researcher interpret from their actions in my life (Kahn, 2011).

Although pseudonym or the use of composite characters can be employed, identifying features may still exist which could enable someone familiar to my family to identify people or locations. For this study I avoided the use of composite characters. I did not see the benefit of making up one character to encompass the personalities of different people. I wanted to stay as true to my story as possible, so instead I have opted for the use of pseudonyms for people and obscured the locations. I have written my story, aware that people close to my family may recognise myself and other characters but I have only provided information that I am happy to share regardless of pseudonyms.

A crucial ethical consideration in this research was the inability for my pre-school children, both Nancy and her younger brother Edwin, to give their informed consent to be subjects in my story. Their anonymity cannot be assured solely through the use of pseudonyms as my name will be associated with the research. However as their mother and researcher I can control what information is shared and believe it is not discussing a subject which would cause undue harm or embarrassment to either child named in the study. I take responsibility for the decision to involve them in my research and its consequences in ways appropriate to my position as their parent and legal guardian, and in light of my understanding of ethical issues as a researcher. Wijayatilake (2012) cites Ellis (2004) noting that we need to be responsible for those we write about but also in writing about others sometimes the greater good outweighs the harm it might do.

Denzin and Lincoln (2005) propose that when writing using an autoethnographic method authors should operate under an ethic of care, solidarity, community, mutuality, and civic transformation. Kahn (2011) writes that autoethnographic authority “results from being able to present details and insights that only the writer would know, because the writer was there and the readers weren’t” (p.184).

Issues of credibility, authenticity and trustworthiness are relevant within qualitative research and autoethnography in particular. However as I am writing my own personal story there is an element of trust in that the reader will interpret my reality and the validity of my research in the same vein in which it is written. Silverman (2000) notes that there is no ‘golden key’ to the issue of truth within qualitative research. My story is a reconstruction of my past, whilst this makes me the best person to detail my experiences it means the traditional, positivist views of validity cannot be applied (Lineham, 2001).

Maykut and Morehouse (2000) believe that ultimately the reader needs to be asking to what extent they can trust what has been written. Lineham (2001) cites Conle (2000) discussing 'resonance' as an indicator of trustworthiness and credibility. In this respect trustworthiness and credibility are implied as the story will conjure up an emotive response through the readers own storied experiences.

This chapter has highlighted how this research is suited to a qualitative autoethnographic methodology. It has detailed what the reader stands to benefit from reading this research written in this method and has discussed the trustworthiness of this method.

## **Chapter 4**

### **Narrative**

#### **Introduction**

The birth of your first child changes you. Before Nancy's birth I was an independent, professional woman. Whilst I was considerate of others, my sole concern was my own happiness and wellbeing. Nancy's birth evoked a range of new emotions and changed how I perceived the world. I was no longer responsible for just myself and my happiness but I was now responsible for another life, one who was completely dependent on me for her physical and emotional health and wellbeing. This transition from independent young woman to mother came with a fierce need to protect my baby and ensure she was raised happy and healthy.

This narrative will provide an insight into the lives and experiences of our family and how we live with and manage Nancy's allergies. Whilst the main crux of my story takes place from Nancy's birth, an initial introductory setup is required for the reader to understand the entirety of my story. It is important I provide some background information about certain reoccurring characters, relationships, and events that need explanation before delving into the account of my life.

#### **Me**

I am of European decent, tertiary educated and the only child of a single mother. My family was very close while I was growing up and my mother and I had great support from my grandparents. My parents separated whilst I was an infant and although my father remained in my life his visits were sporadic. It was not until my teenage years that I had regular contact with him. On saying that there was always a lot of love in my family and a lot of love between my father and me.

I have always kept good health. I would tell people that I had the 'bomb' immunity because I never had chicken pox, measles or mumps, no history of childhood asthma or allergies, nothing that kept me away from school or work for any extended periods of time. That was until I was 25 when I was diagnosed with and treated for cancer. I had an Acinic Cell Carcinoma of the parotid gland which resulted in major surgery, a facial nerve transplant and seven weeks of radiotherapy. My treatment finished two weeks before my scheduled

wedding on a tropical island. I was informed that I would not be physically fit for a wedding or overseas trip but in what was termed “true Cassie fashion” I came through everything really well and the wedding went ahead.

Nancy was a planned pregnancy after discussions with my medical team reassured me that the chance of my cancer returning was similar to that of people who had never had cancer, and that my type of cancer was what was termed “bad luck” and not hereditary. I became pregnant approximately seven months after the completion of my treatment. At the time I was feeling fully recovered and back enjoying normal activities of daily living. My husband and I were living on our own with a pet Labrador dog named Georgie. We called her our first born.

I am a registered nurse and although I am currently employed two days a week as a nurse educator at a training institute, at the time of Nancy’s pregnancy I was working as a nurse in an operating theatre. My husband and I own our own home (with a mortgage) and are what could be termed ‘middle class’.

#### **Eddie: My husband**

My husband, Eddie, is also of European decent and tertiary educated. He is one of three children and has one stepbrother. He is close to his mum, dad and step-father. He works as a Physical Education teacher at a local secondary school. In 2010 a serious gastric infection caused him to be admitted into our local hospital for three nights. Following this he continues to experience symptoms of Irritable Bowel Syndrome which we control by maintaining a strict gluten-free diet.

As a child Eddie experienced serious asthma and eczema for which he was on a range of medications. He grew out of both of these ailments in adolescence. As a child he also got salmonella poisoning which resulted in him having six weeks off primary school.

#### **Nancy: My daughter**

Nancy was an uneventful pregnancy and hers was a natural birth following induction at ten days past her due date. She was breast fed for ten months and topped up with formula after each feed from the time she was five months old. She was also started on solid food at five months old. At her post-birth hip check it was discovered that she had congenital hip



dysplasia (CHD), commonly known as 'clicky hips', which resulted in surgery. She underwent a femoral tendon release and the application of a hip spica, which is a cast from just under the nipples to the ankles; this corrects her CHD by keeping the hips adducted. Nancy had this in place from four and a half months of age until she was nine months old and has no on-going concerns related to her CHD.

Nancy tried egg for the first time when she was eight months old, following feeding advice from a Plunket Nurse who advised us to commence Nancy on whole eggs. This resulted in her first allergic reaction and hospital admission. This was the beginning of our journey into living with allergies. Nancy also had surgery in 2012, at three years of age she had a tonsillectomy, adenoidectomy and grommets inserted. She had glue ear and sleep apnoea which her surgeon attributed to the enlarged tonsils and adenoids.

Nancy slept through the night from a young age. She was easy to get into routine and has always enjoyed food, eating a varied diet. She appears to be a happy child who enjoys socialising with her friends. When she was approximately seven months old I commenced employment as a nurse educator working two days a week. This resulted in Nancy being placed into our local pre-school whilst I was at work. It was a difficult decision to make to put her in care given her allergies and that she was still in the hip spica, but financially we required the money.

### **Edwin: My son**

Like Nancy, Edwin's was also a natural birth following induction at 10 days past his due date following an uneventful pregnancy. He was born approximately 26 months after Nancy. He was breastfed until he was eight months old and topped up with formula after each feed from 2 months old. To date he is a very healthy child apart from having infantile eczema, which he grew out of at approximately six months old. He has shown no signs of allergies or any chronic illnesses.

When he first developed infantile eczema I became almost inconsolable. He was red raw over his entire trunk and I started to imagine a long road ahead, not just dealing with the eczema but I was also aware that this could indicate he would have allergies. I became scared about how to introduce him to solid food. When I consulted our local doctor her response infuriated me. She just shrugged off my concerns and I felt like I could hear her

internal dialogue telling me to “get over it” and “it’s just eczema”. She was very unreceptive to my fears about introducing him to solid food or my requests to be referred to an immunologist. I was instructed to just try each new food individually and see what happens. Whilst this might seem to make perfect sense to everyone else, it made me want to scream. I had tried the normal progression of food with Nancy and it could have killed her, so how was I meant to feel comfortable about doing this with Edwin? I felt deflated at this time in my life. Then one day his eczema just disappeared. My relief was overwhelming. I had watched my friend try to manage her son’s severe eczema, which is exacerbated by his allergies. I have seen her cry and stress over eczema and allergies and had always felt lucky that I only had to worry about Nancy’s allergies which, although they were more severe, they weren’t linked with eczema.

Edwin was difficult to get into a routine and did not sleep through the night until he was well over one year old. He first tried solid food at five months old. I had read one hypothesis about reasons for the rise in numbers of children with allergies which said that the food preparation has become too sterile, that babies now eat more store brought canned baby food. Twenty years ago babies would have been eating food their mothers had made or being given a taste of something she was eating, therefore receiving antibodies from her saliva. With that in mind I decided to “bird feed” Edwin. I know it sounds gross but Edwin’s first taste of new food was when I was eating something. I would mush it up in my mouth and then let him taste it. I’m not sure what my friends or anyone else thought of this but it did help ease my increasing anxiety.

Edwin remains a fussy eater. For a year he would mostly eat bananas, and I still struggle to get him to eat a varied diet. I can’t help wondering if that is because he picked up on my fears and stress at trying him with food. I can remember mashing chicken and vegetables into his bananas to try to ensure he had a balanced diet. Although he eats a varied diet now, he is still fussy and is yet to try any allergy prone foods such as egg, peanuts or tree nuts.

Edwin is also a happy child although more clingy to me than Nancy. I returned to work as a nurse educator when Edwin was 11 months old. He also attends our local pre-school with Nancy whilst I am at work. I did not feel the same level of guilt returning to work this time as Edwin was older than Nancy had been, and I have seen how much Nancy enjoys pre-

school. On saying that, he gets very upset when I drop him off so I get Eddie to do it most days.

### **Extended family**

We are a close family unit. My husband and I moved from Christchurch to our current home in 2004. The birth of Nancy saw my mum relocate to be near us and the Christchurch earthquake in February 2011 saw Eddie's mum and step-father move here also. My father passed away from liver cancer in July, 2013. He was living in another South Island city and regularly visited. Eddie's father still lives in Christchurch and also visits regularly. Eddie's father was diagnosed with prostate cancer in 2012 which has been treated with surgery and he is now in remission. Both Eddie's mother and father are on medication for high cholesterol but other than that everyone keeps good health.

Having my mum and Eddie's mum and step-father living nearby provides us with good support. They are regular sounding boards for our fears and frustrations and, to date, apart from pre-school staff, and very close friends, they are the only other caregivers for our children.

### **Pregnancy and birth**

As a nurse I am accustomed to reading research and "finding out" the finer details of what I am doing within my professional career. I had this same view with regards to my pregnancy: I wanted to know everything about every stage and ensure that I was meeting all of the needs of my unborn baby. I think that, alongside my natural tendency to research information and the fact that I had just recently finished treatment for cancer, I became overzealous with my need for information.

I remember wondering "I feel good but is my body really up to this?" Eddie had also questioned whether what I had gone through would have affected my eggs. I cannot remember who said it, I think it was Eddie, but I remember someone asking "could the radiotherapy have cooked or altered your eggs?" At the time I am sure that was probably said as a joke, although a bad joke. However the question always stayed in my mind and still makes me feel sad, leaving me questioning whether my body was up to pregnancy and childbirth alongside the pressures of being a new mum.

My medical team disputed the thought that the radiotherapy would have affected my eggs. The only effect they were concerned about was that I would be tired and, if anything, that it would only affect my ability to get pregnant. However the thought that something could be wrong with my eggs and that I had rushed into getting pregnant never left me. Even now I find myself wondering if Nancy's allergies and sleep apnoea is because I was in too much of a rush to prove to everyone I was ok. "See I'm fine, I can even have the baby I always wanted".

Pregnancy and birth is one area where there is an abundance of research and opinions. Not only was everyone sharing their opinions about my pregnancy with me, but I was reading everything I could get my hands on. I remember reading one book that said dairy was not intended for human consumption and should not be eaten or drunk in pregnancy, so I stopped having dairy in my diet. Then I read that I needed a larger amount of calcium so I was living on spinach and anything else that could meet my calcium needs but didn't contain dairy. This was just one example of how extreme I was getting. It was not until my midwife sat me down and gave me a stern talking to about what my baby's needs were that I started to relax. I can vividly remember her telling me, "The people who come through pregnancy and birth the best are teenagers and young mums...they do not tend to read too much and overthink" which is what she said I was doing. She instructed me to avoid the "risky foods" and then continue life as normal, with just a few obvious restrictions.

Once I started to relax, Nancy's pregnancy was easy. I never got any morning sickness, continued to go to spin classes and exercise up until the last few weeks, and maintained my "on call" work responsibilities until 37 weeks gestation. At ten days over-due Nancy was induced and was born at 0800 hours the next morning. I will never forget how it felt the first time she was placed in my arms. Eddie was beside me with tears of love and admiration for both of us. I can remember one friend had previously warned me that I might not love her instantly the way it is portrayed in all the movies. She said she felt this amazing need to protect her child, but the love grew over the next few days. This was not the case with Nancy. She was perfect and I knew at that instant that I loved her with every ounce of my being. I was a changed woman from that moment.

### **Life up to Nancy's first allergic reaction**

After Nancy's birth I felt amazing. We decided that I had gone through everything really well and I wanted to go home so we were discharged from the hospital shortly after 12pm that same day. I was just itching to get home and start our new life all together. Also, at the time, swine flu was causing visiting restrictions. I was only allowed one visitor at a time and this included Eddie, so when my mum or Eddie's mum wanted to meet Nancy, Eddie was meant to leave. This made me more determined to be discharged and take our beautiful new baby home.

I was going to be Super-mum. I had goals of maintaining a tidy house, breastfeeding exclusively for at least a year, restarting exercise within a short time and getting my pre-baby figure back. I was going to include Nancy in everything and develop her through play whilst cushioning her from some of the hard realities of life. I was full of the best intentions.

Six days after Nancy's birth I received a phone call telling me that my Nana was dying in hospital. Nana had played such an instrumental part in raising me so this was devastating news. Nancy, Eddie and I boarded a plane for Christchurch that night. Whilst waiting to board the plane a woman came up to me and told me that I should be at home and there is no way a baby that young should be on a plane, especially in light of the swine flu epidemic. When this woman first came up to me I thought it was because she wanted to congratulate me on my beautiful daughter. It amazes me to this day how other people can feel so righteous about sharing their unsolicited opinions, with little disregard for how it might make another person feel. I have never forgotten her. I saw my Nana on that trip but I did not return for her funeral. I sometimes wonder if what that woman said played a part in that decision. Reflecting on this now I am dismayed at how much the opinions of others affects me.

After that, life went back to normal. Eddie went back to work and I stayed at home trying to figure out how to be a mum. Initially I felt quite bored. Nancy would go to sleep and although I should have probably tried using that time to catch up on some sleep I would clean instead. It became routine. Nancy would wake between 0600 hours and 0700 hours and feed, I would get her dressed then she would go back to bed at 0900 hours. I would

then use that time to vacuum and every morning I would steam clean the carpet, whether it needed it or not.

I'm making it sound like I fitted into motherhood really well, but the truth is I found the transition from a confident, professional woman to being a mother difficult. I often felt at a loss for what I should be doing. When Nancy was asleep I was bored, when she was awake I was questioning how and what I should be doing to entertain her, and when Nancy was unsettled I questioned every decision I made. I do not want to make it sound like this time in my life wasn't enjoyable; it was just a big transition and I was on a steep learning curve.

When Nancy was diagnosed with 'clicky hips' I was sure it was in some way my fault and although Eddie never blamed me I was sure he thought that as well. As I wrote that sentence I was aware that the ongoing dialogue in my head has sparked up and I am asking myself, yet again; Am I a good mother? More bad luck? Why me? I am finding that these statements are quite repetitive throughout my story. When my little four and a half month old baby came out of surgery in this big spica cast I thought we would never cope. She didn't fit into our car seat or pram, there was just a small hole in the cast to try and change her nappies and she would not be able to attempt to sit, crawl or stand until the cast came off at nine months. I was so worried about how this might delay her meeting those crucial developmental milestones. How was I going to even try food? What if solid food gave her diarrhoea and it went all through the cast? How were we even going to try it, she can only lie down? I had no idea how to manage the cast and very little information was supplied. In fact the only information the hospital had given us prior to admission was to buy a car seat for toddlers. We were told nothing about brands or widths. When we were discharged the next morning we were devastated when Nancy couldn't fit in this purpose-brought car seat and we were stuck for how we would get her home. Fortunately a friend of mine was at the hospital visiting us at the time and we were able to swap car seats with her in order to get Nancy home.

Again life returned to normal very quickly. Although we had never been put in touch with any other parents or support groups I found my circle of friends was great. They arranged a welcome home afternoon tea and gave Nancy toys she could play with on the floor or stationary. Eddie and I had previously ensured Nancy had had plenty of 'tummy time' so she was used to being on her front. I found a front pack which I could carry her around in

instead of a pram and we used a bean bag to prop her up on to feed her. The cast added an extra kilogram to Nancy's weight, but that didn't slow her down. At six months old Nancy was dragging that cast around crawling in an army crawl fashion. We were both incredibly proud of our determined wee girl.

Most people were very gracious and would accommodate us. At supermarkets people would often invite us to go ahead of them at the checkouts, as Nancy did not fit in a trolley and it was awkward carrying her and pushing the trolley. By the time she got to nine months old she was getting very heavy. Occasionally people would stare, and sometimes I could hear their internal dialogue asking "what happened to that poor wee baby?" I ignored these looks most of the time, and they never really worried me. However there was one time when I was feeling fed up with it so I turned to a woman who had been staring and told her that Nancy's father had dropped her out of a tree and I promptly walked away thinking I was hilarious. Eddie would not have been impressed if he had known.

When Nancy was eight months old a Plunket nurse asked me if she had tried eggs yet, and instructed me to feed her on whole eggs. I remember asking should I try egg white or yolk first, as this is what my mother-in-law had previously instructed me. But the Plunket nurse said that the latest research suggested just giving infants whole eggs and as that was easier than trying to separate them that is what I did. Sitting here writing this down I feel immense guilt. Irrationally, I call myself lazy and selfish. If I had just separated the eggs her body might not have been assailed by the different proteins in the whites and yolks. She may never have developed her allergies and wouldn't have ended up in hospital. The rational part of my brain is kicking in now and is reassuring me that she still might have developed her allergies, and I was just following advice from someone whom I thought knew best. That is what my brain is like when discussing or thinking about Nancy and her allergies, one side blames me and the other side pacifies me. Following the advice from the Plunket nurse I made Nancy scrambled eggs. I then left Eddie to feed them to her and drove away. I had not gone very far when Eddie called me on my cell phone to tell me something was wrong, Nancy had vomited, gone red, and was screaming.

I want to say that my mother's instinct kicked in and I knew something was wrong so I sped home. I did head home, but the truth is I was irritated. I very rarely went out and I was

going to participate in the 'Relay for Life', a fundraiser event for the Cancer Society. I remember thinking "Oh my god, she better be sick because if he has called me back because he cannot cope with her being unsettled I will scream". I got home within a few minutes and it was easy to see something was wrong; she vomited again and was beginning to swell up.

Here goes the irrational brain kicking in again. 'What kind of mother would give her baby a new food, especially eggs, and leave? Didn't you love her or were you just wanting time out for yourself again?' Now time for the pacifying side to have a say 'You didn't know or suspect that would happen. Yes you have friends with sons that are allergic to eggs but you never think bad things are going to happen to you. You still came home as soon as Eddie called, it's OK, and everyone knows how much you love her.'

Having worked 'on call' for the hospital I knew it was seven minute drive from our house. This meant that we would get there before the ambulance would get to our house. We got straight into the car and drove to the hospital.

### **Diagnosis and impact**

Trying now to remember what happened when we were at the emergency room is a bit of a blur. I remember ringing my mum but reassuring her that Nancy was stable and maintained consciousness and an open airway. Doctors gave her drugs. I now know that they would have been antihistamines and steroids to assist with reducing the swelling in her airway but at the time it was hard to determine what was being given to her. Old colleagues came up and made polite conversation. Externally I think I remained quite calm, I don't remember crying or being too stressed. Internally I was freaking out. I remember thinking, "I'm sure one of the doctors said allergic reaction but it won't be, it'll be cancer or something terrible, we will have to go to Starship Hospital, and I'll resign from work..." and so on. I am terrible at letting my thoughts snowball into worst case scenarios. At the time I had no idea that having an allergy such as Nancy's could be one of those 'worst case scenarios'. Allergies just sounded so common, like 'hay-fever'.

After being medicated Nancy slept on me in the emergency room and then we were transferred to the Paediatric Assessment Unit (PAU). The doctor who saw us in PAU was also training to be a lawyer; I can remember wondering why would anyone make that kind



of transition? It's funny what gets remembered, whilst at the same time I cannot remember his name or any of the other finer details of Nancy's admission. One of the side effects of allergic reactions is urticarial and this doctor commented that Nancy had the worst case of urticaria he had ever seen. Urticaria can be simply described as 'hives' but that sounds far too simplistic. Nancy's skin was so swollen and red that Eddie and I were sure her hip spica cast was going to have to be cut off. It actually left pressure areas at her ankles where they had swollen too much into the cast. That added a whole new stress to the situation. At the time I was so worried about how removing the cast would impact on Nancy. Would having the cast cut off early affect her recovery or would another cast be reapplied and would this extend the time she would have to be restrained in a hip spica? Nancy had stopped vomiting before we came into hospital, but she was left exhausted and slept on me for the majority of that day and night.

Slowly her swelling reduced, her hip spica did not have to be removed and over the course of that night she returned to her normal smiley self. But the implications of a restricted diet for her were starting to sink in. There were a million questions but very few answers. I came away from that admission knowing that we would be referred to a paediatrician for further testing and that we shouldn't have to wait too long as, although we did not have medical insurance, her reaction was so severe that they would prioritise her referral. I was told I should continue feeding Nancy the foods she had already commenced but I was not to introduce any new foods, and that I could continue to eat all foods myself, including eggs, even though I was still breast-feeding her. This later advice is still contested in many forums. A lot of mothers completely eradicate certain foods from their diet whilst breastfeeding. However following the advice I was given I continued to eat a varied diet including eggs. As I reflect on this now I realise that this is about the time I started to introduce more formula and within two months of Nancy's exposure to eggs I had given up breast feeding. I can remember saying to a friend that 'the question over whether or not I should continue to eat those foods was a good reason to give up breast-feeding Nancy, and that 'it was too much of a tie anyway'. But as I write this I feel a little bit sad. At one point my story describes an idealistic new mother who was going to breastfeed for at least one year and another where I gave up earlier than that.

I guess in a way I was fortunate. Two of my best friends also had children with severe allergies to eggs, both of whom also carry adrenaline auto-injectors and they have had to

deal with asthma and severe eczema alongside their children's allergies. They were a tremendous source of information and support especially in those early days. But yet again I was left feeling like I had a new baby that I had to try to figure out how to care for. In truth it was easier then. She was only eight months old, I could easily control her diet and exposure. My biggest fear at that time was that she would go on to develop eczema and asthma which I'd watched my friends trying to manage at a huge financial cost and emotional strain. I was so worried that she would develop this disfiguring condition that the actual allergy seemed less of a concern. Nancy did develop these but fortunately she only ever gets minor patches of eczema and minor asthma.

Our paediatrician appointment soon arrived. Radioallergosorbent (RAST) blood tests had shown that Nancy was highly allergic to egg white, egg yolk, peanuts, tree nuts and dog dander, with a mild allergy to dairy. This did leave us in a bit of a head spin! What did it all mean? Our paediatrician was great at explaining the risks, and stated that although Nancy maintained airway at the initial exposure, and was able to be easily treated with antihistamines and steroids, it is often the second exposure that can initiate a full anaphylactic reaction so careful attention to exposure needed to be ensured. He also explained the difference between an egg allergy and nut allergy by using a car analogy. He stated that an anaphylactic reaction to nuts was like a supercharged car and an anaphylactic reaction to eggs was like a V8. A V8 is still fast and powerful but nowhere near as quick as a supercharged nut reaction. From that conversation we got to understand that an exposure to nuts would require very quick treatment, whilst with eggs we would have a bit more time to observe and treat symptoms as they arose. He then prescribed us adrenaline and sent us to meet the outreach nurses to learn about how to draw up and give adrenaline. He also informed us of our options for purchasing Adrenalin auto-injectors such as EpiPens. He recommended that we carry both and informed us that we can purchase EpiPens at online Pharmacies.

So this is what we did - we learnt how to give injections. As I was a nurse I did not require instruction but my husband had no experience with needles nor with giving injections so the paediatric outreach nurses went through the steps with him. Once he had drawn up the medication, which for this simulation was just normal saline, he then had to inject it into my leg. This was so he could experience both giving the medication and also injecting someone he loves. I freaked out! Watching him come at me with a needle caused all sorts

of fears to surface and next thing I knew I was crying and refusing to have it done. On the other side he thought this a fabulous idea and was almost holding his stomach whilst laughing at me. I knew it had to be done but I hated it. Needless to say I eventually 'swallowed my tough pills' and allowed him to inject me, tears and all.

We left the hospital with a prescription for five vials of adrenaline, syringes and needles. This scared me as Nancy was to have just 0.13mL of the vial which came in a 1mL quantity. Being a nurse I know how easily mistakes can happen amongst professionals and how much work goes into ensuring they do not. Here we were, after a one-off lesson, with way too much medication in each vial. Even scarier was the fact that we were told just to show grandparents and care givers how to give these injections. These are the other people responsible for looking after Nancy, surely they required more than just us showing them. So I went home and made up packs to keep in our cars and for at the houses we regularly visit. In the packs were everything required to give an injection, and step-by-step instructions I had written from what I remembered from the session with the outreach nurses and what was written on the prescription. I felt like adding a final step to my instruction, 'cross your fingers'. I don't know how people without a medical background cope with all the information. Maybe it's easier for these people as they are less likely to understand how easily it can go wrong.

We also purchased an EpiPen online. To this day it amazes me that this is allowed to happen. We purchased an EpiPen Junior which is what I remember the paediatrician recommending. For two and a half years we purchased these pens, every 11 months when their efficacy expired, one for us and one to leave at Nancy's pre-school. It was not until Nancy was three years old and we saw a different paediatrician that I discovered she had been too young for an EpiPen and the dose on the ones we had brought would have overdosed her. I can remember thinking "we are damned if we do and damned if we don't".

### **Management – day to day life**

Learning how to manage allergies is something I am still dealing with almost four years after Nancy's diagnosis. There is so much to consider on a daily basis, and in the back of my mind is the fact that if I make a mistake it could mean my child is exposed to an allergen and the consequences of that are terrifying. I am still conflicted about how much I do and

how much I should be doing. It can be, at times, a massive internal guilt trip for me, especially when I compare my mothering practices to those of friends of mine whose children also have allergies.

I watch my friend Renee manage her son's allergies. She is so organised and thoughtful. Every night she bakes soy-free bread and constantly has a supply of baking on standby in case there is a birthday party or shared lunch; this way her son does not feel left out. The other day I was visiting her whilst she was making soy-free and egg-free chicken nuggets and sausages for him to eat at a school sausage sizzle. I was in awe of her and felt incredibly 'slack' as a mother. I had just taught Nancy that if she is at a birthday party she can't have the cake or some of the other food. I watched Renee and images of Nancy being upset at not being able to eat cake or other foods with her friends flashed into my mind. I find myself constantly torn between what is the best course. Do I bake her foods so she never feels left out or do I help her learn that is life, there are foods she can eat and foods she can't eat? Even as I type this I feel as though I am being a bit hard on her; she has only just turned four. If I think logically for a minute I can assume all mothers probably compare themselves to other mothers. My friends and I often talk about 'mothers' guilt' but Nancy just has so much more riding on me being organised so that she doesn't get exposed to allergens.

The truth is that I do always have egg-free and nut-free food on standby; that is the nature of living with allergies. But is very rare that it's homemade and as tasty as what Renee gives her son. Having a supply of suitable food is something I have to do, I keep a 'safe' of food in my hand bag and in my car. This is a necessity in case we are out or visiting and there is no food that I can purchase or give Nancy that is free of her allergens. It is not uncommon to find dairies that don't even sell fruit so finding healthy foods that I can give Nancy whilst out running errands can be impossible sometimes.

I have tried so many different recipes but it is not often that my baking works out, so instead I have potato chips, store-brought biscuits, fruit and fruit bars that I know Nancy can eat. Approximately two years ago Eddie contracted a stomach infection which left him unable to tolerate gluten; this coupled with Nancy's allergies makes baking a real challenge and has become a good excuse for why I do not bake.

Cooking tea is an exercise on its own. Trying to cook one meal for the whole family is impossible sometimes. This means that often I am cooking two different versions of the same meal or cooking different meals all together. Gluten-free food often requires eggs and nuts to improve the taste. All store bought gluten-free bread contains eggs, and as a lot of my recipes for Nancy contain gluten, it can be incredibly frustrating. In all honesty, though I am working with it, two years of experimenting with recipes has taught me a lot about what I can or cannot do. But all of this means I tend to stick with the recipes I know because it makes experimenting with new meals and baking difficult. Often I just want to put it in the 'too hard basket' but then I just end up feeling like a terrible mother. I want my children and husband to have a varied and healthy diet that they enjoy. There is an increased financial cost also, especially when buying Eddie's gluten-free food. But all foods that are marketed for people with intolerances and allergies are so expensive and I shudder to think about how much money I have wasted on food I have thrown out because I tried to cook or bake something that ended up tasting terrible.

One of our biggest financial burdens and constant frustrations is that the adrenalin auto-injectors, such as EpiPen or Anapen, are not funded by the New Zealand Pharmaceutical Management Agency (Pharmac). Pharmac is the Crown entity that decides which Pharmaceuticals will be subsidised for use by community and public hospitals in New Zealand.

The expense of these adrenaline auto-injectors is considerable. A quick internet search for online New Zealand Pharmacies showed the average price of \$135.00 for EpiPen and \$99.00 for Anapen (the two adrenaline auto-injectors available in New Zealand). Both these auto-injectors expire within 11-14 months. The problem is you really require more than one. We keep one at Nancy's pre-school and one in my handbag (or left with her if she is with someone else); ideally I'd also like one in the car for emergencies as well. This means that we spend between \$198-270 a year on auto-injectors which, all going well, eventually just get thrown out. I feel fortunate that we can afford to do this. My husband and I both earn enough money that although it hurts we can afford it. I can only imagine how it is for people who earn less than us. And although I know there is the option of drawing up the adrenaline and injecting it yourself, I also know how difficult that would be if it was Nancy requiring it during an anaphylactic reaction, and I am a trained nurse who has given many intravenous and intramuscular injections.

On top of the cost for the auto-injectors and specialised food is the added cost for all the creams and hypoallergenic washing powders and different potions you hear about on the internet. I know I have spent a small fortune on trying different lotions and creams for Nancy's dry skin and eczema patches. And then there is the time. I know it sounds ridiculous as all parents invest time into their children but there are added time demands for parents of children with allergies. After almost four years since Nancy's diagnosis, going to the supermarket still takes so much longer than it would if Nancy and Eddie could eat common foods. I have to read the back of any new food products before I can purchase it and I always double check again before I give it to either of them. If visiting people and they offer food to Nancy I always have to ask to read the food label. I have even had to go through the rubbish to find thrown out packages because Nancy had been offered something that she really wanted. Going to food outlets like McDonalds, KFC or Chipmunks requires taking a packed picnic and then a long explanation to staff as to why I have brought food into their establishment. At times it feels like food and food products dominate my days.

One of the hardest things about Nancy's allergies is her allergy to dog dander. It means that we should not visit anywhere that has dogs inside or, if we do, we should give her antihistamines prior to going. This is incredibly difficult. Apart from Renee, whose son is also allergic to dogs, almost every one of my friends has a pet dog. It is not as simple as asking people to put the dog outside and vacuum; dog dander lives in the carpet and takes years to eradicate. Dog dander will not cause an anaphylactic reaction for Nancy but it causes her to become wheezy, requiring Ventolin Inhalers, allergic rhinitis, and eczema patches. It's not life threatening but it is uncomfortable for her. We recently went to visit friends in another city and had to leave after one night because Nancy just could not cope with the exposure to their dog.

This also meant we had to give Georgie away which was one of the most heart-breaking decisions we had to make. Georgie, our chocolate Labrador was our baby before we had babies. Nancy and Georgie were best friends from the moment Nancy was born. Georgie would lie beside her and just watch her for hours. As I type this I can still feel the pang of sadness at giving Georgie away. When we met with the paediatrician he said if there were no visible signs of allergy he would keep the dog, but when Nancy was two we decided it was not fair on her anymore. Nancy had lots of colds as a toddler and we worried that the

cause of these was a weakened immune system due to exposure to Georgie. After Nancy turned two years old her reactions worsened and she would come out in patches of urticaria whenever Georgie would lick her, which Labradors like to do a lot. I found myself constantly yelling at Georgie to “go away” and then feeling guilty. In the end we decided it was better for all if we gave Georgie away. It was incredibly sad and emotional. We had had Georgie and loved her for over six years. Again I felt judged by people. My internal dialog was saying “You’ve had her around your daughter for over two years, she can’t be that allergic or else why haven’t you done something sooner?” We gave Georgie away one week before Edwin was born and the day after we gave her away we got a miniature poodle. We had previously tested Nancy and found that she didn’t react to the wool of poodle as opposed to the fur of Labradors.

It was a crazy, busy time and in hindsight we should have waited before we got another dog. But I was so worried Nancy would miss Georgie and feel animosity toward Edwin, as he was going to take up a lot of my time. I was wrong, Nancy was so infatuated with Edwin that she hardly noticed Georgie was gone and our poor new dog got reasonably neglected for the first year of Edwin’s life until things settled down a bit.

Georgie came back to visit one day. We were going to look after her whilst her new owners were away but Nancy’s reaction was severe. Within an hour she was wheezing so badly and patches of urticaria were forming. We had to leave Georgie at my mother’s place instead. This was a huge relief for me. I finally felt justified in my decision to give Georgie away.

Nancy rarely talked about Georgie after that, then randomly a couple of weeks ago Nancy brought Georgie up in conversation. We had just finished singing a rhyme about wishes and were talking about all the things we would wish for when Nancy said, “I wish Georgie didn’t die.” We had never said that Georgie was dead but I guess that is what she thought. This was two years after we had given Georgie away. I was so taken aback that I didn’t comment on it. I said that I missed her too and then went on to say what I would wish for. Nancy’s comment blindsided me and highlighted how much their young brains absorb and how much I had taken for granted. Things that were out of sight were not necessarily out of mind.

### **Caregivers and reliability – fear and isolation**

Nancy's allergies became more socially isolating as she aged. When she was first diagnosed it was easy to control her diet but as she got older the true nature of her allergies and how they impacted on even the most basic of daily living tasks became more apparent.

Community picnics or birthday parties became a common source of stress. But trusting someone to look after Nancy was the biggest source of stress for us.

Leaving Nancy at pre-school, where she was in a separate room for children under two years old, took a lot of trust and courage. Fortunately we had a great relationship with the teachers. The pre-school is a nut free space but eggs and egg products have always been allowed. That was never a great concern for me but I was often upset by how the staff gave the children their lunch. The children all sat at communal tables with their lunch in front of them. This often meant that there was unintended sharing or stealing of food. The teachers always watched the children but I never felt comfortable about it. However there was no alternative that I or they could think of. The thought of Nancy being isolated at her own table for meals was just as upsetting.

The under two year olds' room at the pre-school has a ratio of one teacher to four children and, in the time that Nancy was in there, there were never any problems. In fact one teacher picked up that one day I had sent Nancy to pre-school with a canned pasta meal which contained egg. This was devastatingly embarrassing for me as I regularly made comments to ensure all staff were mindful of Nancy's allergies and although it was brought to my attention in a very kind, understanding and caring manner, I felt as though they all would have been thinking about what a terrible mother I was.

Nancy transitioned into a room for children aged two years and four months to four years old not long after Edwin was born. This was done gradually so she learnt about the new environment comfortably. This room had a teacher to child ratio of one to eight. I had become so comfortable with the pre-school that my emphasis on Nancy's allergies had decreased. As it seems to go, the minute you think you have everything sorted life has to remind you otherwise. A new teacher was handing out cake to all the children. Nancy would have been three years old at the time. I was informed that the teacher had given a slice of cake to Nancy and that Nancy had gone and hid in the toilets to eat it. At this time Nancy was quite aware that she could not have anything with egg or nuts in it and this



included most cakes. When the teachers found her she had eaten approximately half the slice. They monitored her and called me straight away. I can still remember the fear throbbing in my ears, the anger and frustration was causing my hands to shake as I drove and I was imagining all the things I would say to the pre-school and that teacher.

However when I got there Nancy was fine and the poor teacher was distraught. She had tears streaming down her face and apologised profusely. She stated she knew what she had done within seconds of giving the cake to Nancy but that Nancy had taken off and it took her a minute or two to find her. I was suddenly reminded of the time I sent Nancy to pre-school with an egg product and the subsequent admissions to the emergency room because of allergen exposure. I, more than anyone else, knew how easy it is to make a mistake and I sympathised with the teacher. Fortunately the cake she had shared around did not contain any egg or egg product. We had all learnt a valuable lesson without there being any on-going repercussions.

Pre-school was not the only form of stress. I can remember someone saying to me that having children can be very hard on a marriage and that a lot of relationships struggle in the first two years of a child's life. My mother once said to me that when children came along I had to prioritise my marriage first. Initially I was taken back. "No way," I thought, "My babies will always come first". But I came to see it as very valuable advice. She told me that if my husband and I are happy and connected in our marriage then the children will be fine and grow up feeling safe and secure.

The trick is that in order to do this you need to have some time away from your children, time where you can feel like a couple again and not just a mum and dad. After Nancy was born this was quite easy, it started with just an hour or two every now and then after she had gone to bed. But as she got older there were occasions when we needed or wanted to be out for longer, and the thought of a night off from being a parent sounded like heaven. But with Nancy's allergies it was never easy. To this day we have never used a babysitter who isn't part of our immediate family or very close friends. Grandparents and very close friends are the only ones who have looked after our children. This is because it's not just a case of explaining Nancy's allergies to babysitters; it's making them understand that nuts and particularly eggs can be found in almost everything. Then we'd have to teach them

about how to treat her should she have a reaction, and there is always the thought that she may develop a new allergy that we are unaware of. It all just seemed too hard.

We are fortunate in that both my and Eddie's mothers live nearby so we do have babysitters we can use, but even family members can bring concerns. I remember talking to Eddie's mother on the phone and she said to me, "Isn't it great Nancy can eat egg now!" I replied, "What? She can't have egg!" It turned out Eddie's mum had dreamt that Eddie had given Nancy egg by mistake and she could eat it, it was fine. Even as I write this I can feel my hands tense and I want to say out loud, "Oh my god...really?"

Visiting Eddie's grandmother also highlighted how little people understand allergies. She had offered us all some baking. When I said Nancy was not allowed anything with eggs or nuts in it she replied that the biscuits were fine and offered them around. As she was doing this she stated that there was, "Just one egg in the baking but it was cooked so it will be fine". I quickly intervened before Nancy could grab the biscuit which made Nancy cry because she thought she was going to get to eat it. Eddie's grandmother kept saying, "But it's baked, she'll be fine won't she?" I maintained a polite disposition but I wanted to scream "YES SHE'LL BE FINE, IF YOU WANT TO KILL HER!" I found myself in a juxtaposition. I had a constant conflict between being over vigilant and others seeming blasé about the potential consequence of Nancy being exposed to allergens. I found myself getting angry with people for not knowing what I knew. As I reflect on this I can see how easy it would be to just give up and isolate yourself out of fear for your child's safety around other people, but I can also appreciate that "you don't know what you don't know".

Even leaving Nancy with Eddie started to see me freak out. I had gone out for a meal with colleagues once when I received a phone call. Eddie had cooked Nancy noodles and one touched her arm before she ate them. Her arm had blown up with urticaria. When Eddie went back and read the packet he discovered that the noodles had egg in them. Fortunately, because they had touched her arm first she hadn't ingested any, but Eddie still felt I should come home in case things began to deteriorate. Another time Eddie gave Nancy a hash brown, something we given her many times before so we didn't really think anything of it, however this was a different brand and it contained egg powder. Again Nancy ended up in hospital and although she also maintained her airway this time it was scary. I was so angry with Eddie, he should have known better. But in truth I probably

brought the hash browns and when I looked at Eddie I could see the stress and overwhelming guilt in his eyes. To this day I can see him sitting beside us in the emergency room, Nancy was asleep on me and Eddie begged me to let her lie on him. He looked so broken and afraid, it broke my heart.

I started to feel so alone. If I can't trust Nancy with family or even my husband how were we going to survive? How was I going to keep Nancy safe? The truth is I wasn't alone; these fears were shared by Eddie. But even as I write this I haven't got the answer. I guess our family and friends are also gaining more knowledge about Nancy and are beginning to understand her allergies better. And I have come to trust them out of a need to. I cannot be with Nancy all the time. I like to have time out, time for myself and time with Eddie, I have had to trust my family. Don't get me wrong though, I have spent many nights awake dreading what could happen, asking myself if I am selfish, am I putting my social needs ahead of Nancy's wellbeing? And I have missed many social functions due to my and Eddie's parents being busy and my refusal to use a babysitter outside of a select few family and friends.

### **Allergy phenomena – misery loves company**

'Misery loves company', that's how the saying goes and it is so true. I'm not saying that anything to do with having Nancy has been misery, but the 'loves company' part of the saying relates well to how I feel about Nancy's allergies. As I've previously stated, raising a child with allergies can feel isolating at times. I feel like a constant annoyance when continually asking what ingredients are in different foods and if people can vacuum and keep their dogs outside if we are visiting. Although all of my friends have been obliging, I am conscious of being an inconvenience.

I was approached by a woman at the local Play Centre I attended, asking if I could help another woman who had been asked to leave her Plunket organised coffee group, as it was too difficult for the other mums to manage her child's allergies. It was heart-breaking to hear this, and made me realise how lucky I have been with such supportive friends. This has perhaps been an easier road for me because of them and the close friends I have whose children also have allergies.

So for me, there is an absolute truth in the saying that 'misery loves company'. I was blessed to have become good friends with three women, prior to us all having children, who all went on to have children with severe allergies. Whilst I wouldn't wish allergies on anyone, it has helped me to adjust to life with allergies because I have friends I can turn to for advice and 'moan bonding' if that's what I need. In return I also hope that I have been a good source of comfort and advice for them. But it does raise many questions for me, as to why we all have children with allergies. Outside my close circle of friends I can name another seven mums who are also raising children with severe allergies.

My mother once worked repairing chipped windscreens and I was amazed at how she could spot a stone chip on a car windscreen from miles away, but I guess you begin to notice what you live. Maybe I wouldn't notice all the mums with separate food containers if I wasn't also carrying them. Whilst I have had many conversations with the mothers I have met because we share something in common it would be easy to say that that is the reason why I know so many people with children with allergies. But as I look through the list of friends I have compiled they are all people I met through different circumstances, completely unrelated to our children's allergies. I have never joined a Facebook group or support group, perhaps the reason is purely because there are more people dealing with allergies as part of their daily lives. I often feel irritated by people's response to Nancy's allergies and most of the time it is the same, especially when talking to my mother's or grandparent's generations. They often reply "Gosh, we never had allergies like that in my day" and as irritated as I feel to hear that, I have come to believe it as true. So why me, why so many of my friends?

The close friends I have whose children also have the allergies, are not within in the same circle of friends as each other. I know each of them from different areas of my life and I have decided to give a brief explanation and description of them and their children to attempt to highlight how widespread and common allergies are becoming.

Renee lives on a farm with her husband and two sons, their oldest has allergies to cow and horse hair, soy and eggs. Although he is not classed as anaphylactic her doctor recommends that she carries an adrenaline auto-injector in case exposure to multiple allergens sparks an anaphylactic reaction. His main complaint is debilitating eczema. I met

and became good friends with Renee when we were both working as nurses at the local hospital before either of us had children.

Layla lives with her husband, three sons and a daughter. Her eldest son has a severe allergy with a high likelihood of anaphylaxis to eggs and peanuts. He also suffers from severe eczema and his parents are required to carry an adrenaline auto-injector. Her two youngest children (twins) are yet to try solids so it is unknown if they have any allergies. I met Layla through our husband's sports team. Prior to the birth of her twins Layla worked as a secondary school teacher.

Miranda also lives with her husband and two daughters. Her youngest daughter has severe allergies to dairy and nuts. Miranda and I met through our coffee group which was organised through Plunket after the birth of our first children. Miranda works part time as an accountant.

As previously mentioned, these women are three of my closest friends. The other seven mums I mentioned earlier can all be grouped together in terms of them being married to their child's father, the children with allergies are not their eldest child, and all mums are tertiary educated. None of these people are friends that I made because of the allergies, nor are they close friends with each other. In other words we are all just mums who know each other through various social networks; we just share a common thread, we all have children with allergies.

When I look at myself and my circle of friends I cannot come up with any reason why we have children with allergies. I can find similarities with a lot of different research and sometimes concur with different research findings but there is not one thing that really makes me go, "That's it, that's why" and I guess without that there will always be that nagging thought, "Was it something I did, or did not do?" The great thing about having so many friends with children with allergies is that we can support each other through those feelings and fears. As I hear myself reassure another mum that she is doing a fabulous job, that it is not easy raising a child with allergies and she must be doing something right because her child is happy and nourished, and that the allergies had nothing to do with anything she did or didn't do, I am also reassuring myself of all of those things.

On top of the reassurance we give each other we have shared advice and what works. This has been of immense value to me because this is one area where I feel the health system has severely let me and my family down. I can honestly say that 90% of what I know about allergies I have either learnt through my own research, chance, trial and error, or through my friends. We share recipes, party ideas, creams that help soothe eczema, hypoallergenic information such as what pets are best for children with allergies, and vaporisers for when asthma or respiratory problems are plaguing our children. We learn from each other's challenges and celebrate each other's triumphs.

### **What I feel we need going into the future**

What do we need going into the future? This is such an easy question to ask but it is a lot more complicated to answer. If I was to sum it up in one word it would be 'security'. I want to feel secure and to have Nancy enjoy the normal activities of daily living which should be afforded to all New Zealanders.

I now have what I dreamed for as a little girl. Although I never felt I 'missed out' by not having my father living with me I would often dream about what it would be like to have the conventional family. I have that now, a happy and secure marriage, a beautiful and happy daughter and a cheeky and playful son, yet I am plagued by insecurity. I lie awake at night sometimes, acutely aware of how quickly and easily my family could become undone.

It often feels morbid but I often cannot prevent my thoughts taking me down a path of the worst case scenario, and how it would crush me and my family. I don't like admitting that I do that but I am often reminded how easily her death could happen and what little control I have over it. In order to feel secure I need to feel that New Zealand society is going to help look after my wee girl and keep her safe, but I fear we now live in a time in which we are often more concerned about ourselves and what other people can do for us rather than what we can do for other people. In May 2013, I was watching 'Breakfast' (a morning news programme on Television New Zealand's Channel One) and the presenters were discussing allergies and how to keep children safe as it was Allergy Awareness week. One proposal presented was to ban nuts and peanut butter from primary and pre-schools. Following this the presenter stated something along the lines of 'Why should my child miss out because someone else is allergic? What is next? Will they want to ban milk because another child has a dairy allergy?' (Christie & Street, 2013). I was enraged listening to this. I implore

those presenters/reporters to become more educated about a topic before they cast their influential opinions to the viewing nation.

I discussed this with a close friend who reminded me that a little knowledge can be a dangerous thing. The media who had at one stage shaped my views on motherhood were now attempting to shape people's views about allergies. My internal dialogue went into overdrive with this. Both Eddie and I discussed emailing the presenters and complaining, but in the end we did nothing. Here goes that guilt again, my internal dialogue again calling me lazy for not contacting them, I just never got around to it. How can I claim to be passionate about allergies when I couldn't even write one email?

Had I sent that email it would have informed them that a nut allergy is unlike an egg or dairy allergy. Whilst an anaphylactic reaction to any allergen will eventually result in the same cascade of responses, the speed is the differentiating factor. Generally an egg allergy is slower but a nut allergy can be fast, in some children almost instantaneous with exposure (which can be just to smell or touch nuts as opposed to ingesting). This can mean that getting treatment to someone after exposure to nuts might not happen fast enough to prevent their potential death. I know about this because Nancy has both nut and egg allergies. Due to the nature of a nut reaction all nuts are banned from our house, however we still allow egg products in the house. We just avoid Nancy's exposure to them.

The television presenter also went on to say that the children with allergies should be alright because they all carry those "pen thingies", alluding to adrenaline auto-injectors. I felt this also showed a lack of research on their part. Adrenaline auto-injectors are not funded by Pharmac. There are children who will not be able to afford that method of treatment and, although adrenaline auto-injectors are deemed to be the gold standard in treating reactions, children can re-enter their anaphylactic state. Adrenaline auto-injectors are not fail-safe nor are they a magic bullet but they will give the child time to get to a hospital for further treatment. This is just one of many examples of how people do not understand allergies and how the general public's lack of knowledge about the severity of allergies affects my ability to feel secure. I felt this was an important example because these presenters (Christie & Street, 2013) had the ability to influence how the general public perceive this issue. Unfortunately I feel their comments probably did more harm

than good when their intention was to raise awareness during an appeal. There is a level of responsibility I felt was lacking in their portrayal of allergies.

So what do I need in order to feel secure? The truth is, unless Nancy grows out of her allergies, I will never feel secure but there are steps we as a community could take to help ensure the safety of children with allergies and decrease my anxieties. Whilst as a nurse I am the first to admit I am tired of the policies and procedures we must adhere to, but as a mother of a child with allergies, this is what I would like to see. New Zealand has no policy for how education facilities such as pre-schools and public schools manage allergies. In fact because allergies are not classed as a disability, children with allergies are not protected from discrimination under the Code of Health and Disability (Health and Disability Commissioner, 2009). Hence a schooling facility has the option of stating that they do not feel they can keep a child with severe allergies safe and decline their admission to the school.

There needs to be guidelines and a mandate about how to manage allergies within schools and policies ensuring the safety of these students. I would also argue that with the number of children diagnosed with allergies being on the rise, there is also a need to ensure schools are supplied with adrenaline auto-injectors and that staff are educated about how to use them. Schools may be the place where a child's first allergic reaction takes place therefore they need to be equipped to manage this.

The health sector also needs to revisit how it deals with allergies alongside how to educate families about how to avoid allergic reactions. I have never seen a dietician nor anyone who provided any education about how to manage nuts and eggs in our family's diet. This option has never been presented to us at any of our hospital visits, although I have heard of other families who have received referrals for their support. Therefore we missed vital education that could have prevented Nancy exposure to her allergens and subsequent admissions to hospital.

No one told us that egg powder was made out of egg; Eddie assumed it was an egg substitute. We found that out by giving Nancy something with egg powder in it which resulted in her being admitted to hospital. Adding to this, I did not know that coconut was in fact a nut and also gave that to Nancy. Fortunately she was not allergic to coconut but I



later found out that in her previous tests it had been grouped as one of the nuts she was allergic to. We also found out the hard way that although the majority of hash browns do not have egg in them, there are some that do. The need to read the ingredients of everything you choose to feed your child is vital; there is no room for complacency when dealing with children with allergies but in this case we had become complacent. We had previously checked hash browns and given them to Nancy without an issue, this time we didn't check and as a result we had another trip to the hospital. The problem is that we found out all of this by trial and error. Fortunately, each time Nancy was treated and discharged but I cannot ignore the fact that the potential consequences could have been disastrous.

There also needs to be a non-judgemental approach to how the health sector treats and educates. Whilst in Accident and Emergency with Nancy being treated for exposure to egg powder, I was made to feel like I had purposefully abused Nancy by one of the nursing staff. Having worked in the hospital myself I always had a level of embarrassment. This was my own feelings and thoughts but I felt people were saying I should know better. As a mother I was already severely judging myself. Healthcare staff need to be aware of this. My husband and I are vigilant about everything that we give Nancy. We do read the back of everything but we made a mistake once that left us feeling embarrassed and disgusted in ourselves, and the reality is it will probably happen again in the future. Healthcare staff need to remember that there is a difference between educating and judging, and that the perception of this can be simply differentiated by the tone of voice or the body language the staff use. As her mother, being judged is one of the hardest things I deal with in regards to Nancy's allergies. I know I am my own worst judge but the learning curve when living with allergies is steep and you have to learn fast. On this occasion some empathy would have gone a long way toward helping us deal with the emotional stress we were going through.

Parents also require education about potential safety issues. What may sound like basic common sense can be easily overlooked. An example would be when I, along with Nancy's pre-school, went out to 'clean up New Zealand', picking up litter from around the local community. A friend of mine who also has a child with allergies was told her child was not allowed to do this for fear that he would come in contact with litter that might have

contained nuts and that this would potentially initiate an anaphylactic reaction. Neither I nor Nancy's pre-school had considered this.

One of the obstacles to my feeling secure is not knowing that Nancy's allergies will be treated properly should she require it. The truth is that adrenaline auto-injectors are too expensive for this to be easily done. I watched a representative from Pharmac on 'Campbell Live' (a television current affairs programme on TV3) that aired in June 2012, argue that treating anaphylaxis by manually drawing up adrenaline, using a needle and glass vial, was just as effective as using an adrenaline auto-injector. For this reason Pharmac would not fund adrenaline auto-injectors (Keane, Hurring, Forrest & McCallum, 2012). The problem is, to effectively treat someone using this method requires that a person or child carries around a syringe, needle and glass vial. Then, on exposure to an allergen and during the beginnings of an anaphylactic reaction, the person breaks the vial, draws up the exact dose and self-injects it into the leg. If the person is a young child or unable to do this themselves it is left up to the parent, caregiver or bystander to be able to do it for them. If that sounds difficult you then need to consider dosage. Nancy's dose is 0.13mLs. Adrenaline comes in 1mL vials. What would happen if I or someone overdosed her? Could treating her anaphylactic reaction cause her to go into cardiac arrest out of human error? Is the bystander aware of this potential risk when they intervene and come to a child's aid?

As a nurse I have drawn up medication out of glass vials under emergency conditions in non-acute conditions many times. I know that sometimes just breaking the vial can be difficult. In fact I have a scar on my left first finger from where I broke a glass vial and cut myself. I can only imagine how the pressure would increase when the emergency situation is your own child's.

I read an internet commentary about allergies and Pharmac's hard stance against funding adrenaline auto-injectors. It argued that the following was needed to increase adrenaline auto-injector compliancy:

- Provide auto-injectors only to GP practices (currently they are available for purchase over the internet or through Pharmacy's without prescription).
- Fund a nurse consultation to ensure that holders of the EpiPen and parents can use it properly (this does not add a lot to the overall cost of the EpiPen).

- Have a recall system in place so that people come in and replace their EpiPen at no charge – and get another “refresher” from the practice nurse.
- Add training in the use of the EpiPen to all the first aid courses.

(MacDoctor, 2012, np)

I fully concur with these suggestions; if Pharmac can fund flavoured condoms then I cannot help but wonder why they cannot fund such vital equipment for those with allergies. Eddie and I were given a one-off training session on how to inject Nancy (using the glass vial and needle technique) in 2010. We have not had any further education since then. Eddie himself admits that he would not have a clue what to do now if it wasn't for my handwritten instructions in our homemade allergy packs. I guess we are in a fortunate position. I am a nurse so I am very familiar with drawing up and administering medications, and we can afford adrenaline auto-injectors.

### **Summary**

I had so many preconceived ideas about what parenting would be like and the kind of mum I would be. I felt like I had done all my homework, so when things did not go as I had foreseen then I felt like life had thrown me another curve ball. Transitioning into motherhood and then a mother of a child with severe allergies was a lot more difficult than I had ever imagined. My feelings of guilt, overprotectiveness, fear, and frustration made this road even longer. I felt abandoned by the medical system put in place to help us and I felt like I was left to ensure Nancy's health with trial, error, and chance. The comforts I had at that time came from my support networks, my husband and family. Especially my friends who were forging a way forward with me, encountering similar issues in the management of their children's allergies.

## Chapter 5

### Discussion

#### Introduction

This autoethnographic methodology has taken me on a journey where I have learnt the benefits of including more varied approaches to nursing research. However to validate my narrative I need vigorous analysis of my experiences. Coffee and Atkinson (1996) believe that the discussion analysis needs to be imaginative, flexible and reflexive. It is not about conforming to one correct approach or set of right techniques. With that said, analysis needs to also maintain a methodical, intellectual and scholarly approach. Graneheim and Lundman (2003) discuss aggregation which is a grouping together of themes under higher order headings as one of the steps within the analysis of qualitative work. Aggregation refers to the abstraction of condensed text whilst still preserving the core value of the original text. With this in mind I have extracted the reoccurring themes from my narrative.

A theme can be seen as an expression of latent content (Graneheim & Lundman 2003). By identifying the themes within my narrative I was able to separate and categorise them into reoccurring themes. The main themes I identified I have categorised under the following sub-headings:

1. The mother
2. The nurse
3. Who is supporting us?
4. Desperately seeking knowledge

Graneheim and Lundman (2003) believe that “the concept of theme has multiple meanings and creating themes is a way to link underlying meanings together in categories” (p. 107). With this in mind I am going to incorporate Gibbs’ model of reflection as a tool to assist the analysis. Utilising this model will be both a creative and methodical exercise (Wijayatilake, 2012). For me there needs to be a swapping of hats as I analyse my experiences. I need to be able to remove my ‘mother’ hat and replace it with my ‘nurse researcher’ hat, but as Wijayatilake (2012) suggests, there may also be times where I need to wear both hats together. Just as two heads are better than one, maybe the same can be said for hats.

As I read through my narrative there were emerging emotional themes. These emotions were related to feelings of self-doubt, a need for approval, fear, anger and frustration, which surprises me as I would normally describe myself as a confident, happy person. In order to ensure my analysis is methodical and scholarly I needed to be able to identify these emotions and reflect on them and include them in a scholarly way throughout my analysis. Through the use of Gibbs' (1988) model of reflection I can analyse my themes, incorporating my emotional response whilst maintaining a scholarly approach. I feel it is of importance to maintain my emotional response as it contributes to a fuller understanding of the issues involved

Gibbs' (1988) model of reflection allowed me to examine:

1. The context, asking me what has happened? Who was involved? Where did it happen? It informs me to reflect in an objective manner both accurately and concisely, and asks if I intend to focus on the structure, process and outcome. My thoughts, what were they, both at the time and afterwards?
2. My feelings, what were my emotions both positive and negative, both at the time and again afterwards? What was I thinking and feeling?
3. To evaluate, how different experiences are managed, were they satisfactorily resolved? What was good about the experience? What was not good about the experience?
4. To analyse different experiences, what are the different factors that affected the outcome, what helped or hindered, can I explain the experiences, why did they happen, how did they happen?
5. To conclude, what might have been some alternative actions or approaches, what could I have done differently (even when things went well), could negative events be avoided, could positive events be made more effective?
6. What will be my future action plan, what will I do if I encounter this kind of situation again, what do I need to learn, how might I learn this?

(Gibbs, 1988. p.10).

Burrows (1995) argues that practitioners need to be able to draw upon practical as well as theoretical knowledge. I have detailed the practical elements of raising a child with severe allergies throughout my narrative. I have followed this by elaborating on those experiences using my theoretical knowledge and applying it to the six steps of Gibbs' (1988) model of reflection. The first two steps were the writing of my narrative in Chapter 4. The remaining

four steps will be covered in the following section. Following step 6 I will elaborate to make suggestions as to how health care professionals could better approach this situation in the future, under the heading 'recommendations'.

## **Reflection**

### The mother

When I reflect on Nancy's first exposure and reaction to eggs it becomes obvious that there is more going on in my headspace than Nancy's severe reaction to eggs. My recent cancer history becomes my initial focus, where I am sure that her reaction will be a catalyst for some greater health issue and I start foreseeing her need for treatment and admissions to the specialist children's hospital. As I write this it is impossible to only wear my nurse researcher's hat. The thought of Nancy experiencing what I went through having had cancer, and reliving my experience through writing this, makes my stomach tighten. I can feel the fear in the back of my throat. It is becoming obvious to me that there is already the need for me to allow both my objectivity and rational analysis to be interwoven with the subjective emotional responses.

Accompanying this fear is an element of what is commonly referred to as 'mother's guilt'. My initial response when Eddie called me to come home was a feeling of resentment. Then when I became aware of how unwell Nancy had become the feelings of guilt become overwhelming to the point where I started blaming myself for her reaction. Not only had I made the eggs but I left her with Eddie whilst she ate them. I then started thinking about what in my history may have caused her to be born with an inability to tolerate certain foods, which added further to the feeling of guilt.

Seagram and Daniluk (2002) conducted a phenomenological study of eight mothers exploring the phenomenon of mothers' guilt. They articulated guilt as the nature and essence of what they described as an "essential component of the mothering experience" (p.61). Interwoven throughout my narrative is also an immense amount of pressure that I placed on myself. I had high expectations to prove to everyone that I was not only 'up to' the challenge of being a mother but also I was going to be the 'best mother' ever. Whenever something tarnished this internal image I had wanted to live up to I felt like I had failed. This added to my feelings of guilt. I ended up feeling like I was failing in my quest to be a 'good mum', let alone 'the best'.

Forssen and Carlstedt (2006) conducted a study into the pressures placed on women within the family context. They found that mothers continue to take on a greater share of child-rearing responsibilities and housework than fathers, often coupled with paid employment. Family life continues to demand more from women than from men. Forssen and Carlstedt (2006) found that this created a conflict of priorities for mothers, especially when mothers chose to take 'time out' for themselves. When mothers did this they felt it was often done at their child's expense. The guilt I felt when I expressed the resentment at being called home during Nancy's first exposure to eggs is a prime example of what Forssen and Carlstedt (2006) discussed in their study. Within a short period of time I went from having some 'time out,' to feelings of resentment, to feelings of immense guilt which still haunts me today.

Swigart (1998) published a book that considered the role of mothers guilt, it highlighted the reasoning as to why women fail to speak honestly about the struggles they may face being a mother. Swigart (1998) states, "To be found wanting as a mother is the worst crime most women feel they can commit"..... "the underlying meaning of this competitive spirit seemed to be a need to reassure themselves and others that they were not bad mothers: that they had done a good job raising their children" (p.103). This resonates within me. Throughout my narrative I flit between allowing myself to relax and express how I was feeling and punishing myself with an internalised ideal image I had of what I needed to do in order to be to be the 'perfect mum'.

Unfortunately, in order to live up to the expectation I had placed on myself to be 'the perfect mother' there is the subconscious expectation that I would have 'the perfect baby/child'. I had read Gina Ford's 'Contented Little Baby Book' (2001). I had memorised the routines she prescribed which, if I followed them, she assured me, I would have a contented baby who slept well and suffered less illness. My internalised image of myself as a mother was affected by my inability to prevent Nancy's allergies. It is hard to now admit this, something I would never have said prior to writing my ethnography, but Nancy's allergies tarnished my internal image of the perfect child which in turn tarnished my ability to be the perfect mother.

Step three in Gibbs' (1988) model of reflection requires that I evaluate my identified theme. When I evaluate what I have written I can see I have two sides to me. When Nancy was admitted to hospital following her first reaction to eggs I say that I remained outwardly calm and I wrote that I portrayed that calmness well to both my children. I can attribute this to my nursing experience. Having worked in highly stressful situations, I know how important it is to keep patients and their families calm and this practice is ingrained within me now. Unfortunately that can be misconstrued by others who think I am confident and inwardly calm as well, so whilst I was busy reassuring Nancy and Eddie no one could see my need for reassurance as well. The panicking mother was well hidden inside my calm exterior.

If I was to objectively analyse this experience, removing myself and looking at it as a nurse researcher not the mother living it, I would say there was a need for me to work through some internal thoughts, especially those related to my fears about my medical history. Reading back over my narrative I can see that there was a need to prove to my friends and family that I was recovered and that I was not going to let the fact that I had undergone cancer affect my ability to live a normal life. If I was a nurse looking after me I would have asked myself, the patient, "have you allowed yourself to fully grieve for what you experienced, the altered personal image, and the realisation that you are mortal? Have you worked through your fears to a point where you can manage them not just live with them?" If I had been asked those questions and responded honestly the answer would have been "no", and as I write this I realise that if I am asking myself this now then the answer would still be "no". I can live and function with these fears, but I have not worked through them or allowed myself to work through my grief. Internally I want to justify to everyone that I am just too busy right now. I think the truth is that I am scared by the thought that perhaps you never get past that fear, and it will be with me forever.

I would also argue to myself that there was a need to communicate more effectively with the medical team treating Nancy and Eddie. I needed to remove my nurse's hat and just allow myself to be a scared mother. I have written that I am frustrated with the medical management of Nancy's allergies but in truth there is that protective mechanism where I try to prove I am coping. If I am projecting a calm and controlled exterior I cannot be too disappointed if people do not know how I am truly feeling internally.



On reflection, along with that fear and the need for a 'protective mechanism', there is the need to delve further into the feelings of guilt. As Swigart (1998) commented, guilt and motherhood are almost synonymous and, whilst it can be assumed that a lot of mothers feel some degree of guilt, I am left wondering why it has played such a big part in my role as mother. Trying to look objectively at my narrative about my life, I can assume that it has a lot to do with my mental health at that time. My fears about my medical history, a need to prove to everyone that I was recovered and a need to be the 'perfect mother' of the 'perfect child', can all be recognised and can contribute to me feeling overwhelming guilt when my life as a mother did not play out as I thought it was supposed to.

In conclusion, what else could I have done? I could have worked through some of my own fears or at least I could have started that process. That may have allowed me to recognise that I was projecting my fears about my health history onto Nancy and creating exhaustingly high expectations about what it is to be a mother. By doing that I was, in a sense, setting myself up to fail. I can sit here now and rationally write that I honestly believe there is no such thing as the 'perfect mother' or the 'perfect child.' But what I cannot say is whether I can write that because I have now been a mother for four years and experience has taught me that, or whether it is because I have both an irrational and rational thought process. My rational brain knows that 'perfection' does not exist, however an irrational part of me still feels an element of guilt at 'not doing more'.

In addition to working through these fears I needed to be honest with Eddie and the medical team discussing Nancy and her allergies. I was not in control, I was scared and I did not know what this all meant. They needed to know that in order to give me the reassurance and education I craved.

So to my action plan. What am I going to do if that situation was to happen again? It is very easy to write that I am going to be honest with my feelings, and let people know when I need reassurance. It is also easy to say that I may look into counselling or some other method to work through my cancer fears and feelings of guilt. If I was solely wearing my nurse researcher's hat then that is where this paragraph would have ended. But the truth is that even though I am aware of my need to do this I am also aware that I have a need to prove I am a good nurse and mother and that I know exactly what is happening in my and my family's lives, that I have not let having had cancer or the physical changes to my

appearance get in my way. I also seem to have an innate need to reassure and pacify everyone else. So although I have an action plan, initiating it and asking for help, or at least a bit of support will be easier said than done.

What I have learnt from my experiences and the advice I would like to pass on to other mothers or caregivers would be to treat yourself as holistically as you do your child. To remember that it is sometimes necessary to put yourself first. Caring for any child but especially those with extra needs requires mental strength. Therefore you need to be feeling emotionally and spiritually sound in order to give so much of yourself to the ongoing care of your child.

### The nurse

Lane-Krebs (2011) discusses the role conflict a mother who is also a nurse can face when her child is critically unwell. Although her article is focussed on the neo-natal period I can relate very well to her findings throughout all of our hospital admissions with Nancy. Lane-Krebs (2011) discusses an overwhelming sense of grief and turmoil that is experienced on both a personal and professional level when presenting with an emergency admission of your child. She delves further into these feelings stating, "Mothers who are nurses often deal silently with a double dose of guilt when their child becomes critically ill, and feeling they have not only failed as a mother but also as a nurse" (p. 37). Reading these findings was like a light bulb moment for me. Those statements resonated so well with everything I had felt throughout our journey with Nancy's allergies. Underpinning my need to appear to be the 'perfect mother' is the need to also be a good nurse. There was definitely an element of not wanting to appear like I could not cope. The people treating Nancy were my colleagues, what were they going to think of me as a nurse if I couldn't even manage my own child's allergies?

Lane-Krebs (2011) elaborates, stating that mothers who are also nurses often struggle with the perception that they 'should have known' (p.37) or 'picked up on the signs and symptoms' (p.37) of illness or their child being unwell. These perceptions often result in a loss of self-worth and self-esteem both personally and professionally. As I read through my narrative I relate to these findings. Throughout my narrative are moments where I argue that I am responsible for Nancy's exposure to allergens and subsequent treatment.

Chaperon (2010) believes that nurses are notorious for feelings of guilt, for not recognising

the needs of family members, and attributes this to the emotional, psychological and physically demanding aspects of nursing.

I would also argue that it is a conflict of nursing roles when a colleague becomes a client. Many of the health professionals treating Nancy forgot that I was her mother and not just another nurse capable of making professional judgments. I should not have been expected to maintain a professional persona. Lane-Krebs (2011) states that the psychosocial needs of the mother of a sick child should become a nursing priority. The mother's emotional needs must be met through the development of a nurse-client therapeutic relationship. There are many times I can remember taking Nancy's vital observations and recording them, not because the nurse had asked me to specifically but because I knew how busy they were and I felt an obligation to ease their workloads.

Shires (1982) addressed the phenomenon of caring for a nurse who becomes a client. She stated that it was not uncommon for nurses to expect their clients to continue to be nurses by either asking professional questions of them or by avoiding them altogether because they either did not require the nurses' council or they were afraid the nurse-client would be critiquing their work. Although this is an old article I related to her statements. I felt all of those findings could be behind why I was not given the level of support I felt I needed. Coupled with this was a desire to still be seen as a nurse and a valuable member of 'the team'.

There are benefits to being both a nurse and a mother. There were times when I could listen and contribute to medical discussions that I know may have been difficult or intimidating for lay people. I knew and could interpret the medical jargon Eddie did not understand. When Nancy needed an emesis bowl or the like I could go and get it instead of waiting for a nurse to answer our bell. I was accustomed to advocating for my patient within my nursing role and that transferred to my role as mother as well. On top of that, whenever Nancy required a different procedure, such as blood sampling, I could explain it to her. The skills I had as her mother and the experience I had as a nurse meant that I was able to comfort her through those procedures.

This leads me to asking what else I could have done, following step five of Gibbs' (1988) model of reflection. This is a hard question to answer. Shires (1982) recommended that nurses need to remember that clients who are nurses are clients first. I would argue that

his statement is still relevant today. There needs to be a professional shift in how we treat our own nursing colleagues. I believe there is a systemic fear amongst a lot of nurses about how to interact with clients who are also nurses. However for me that statement is also true in reverse as well. I needed to remember I was a client and mother, not another nurse on the ward, the perception that I was expected to help may have been self-imposed.

As for what I could have done differently? I could have articulated with my colleagues exactly how I was feeling. I could have trusted them and respected their professionalism more. The rational side of my brain knows that they were not judging me, my mothering ability or my nursing skills, but by portraying that I did not need their assistance meant that I may have been making them feel excluded and unnecessary.

So what would I do if I was in the same situation again? I need to relax and in a sense ‘turn off’ the irrational side of my brain. I need to re-orientate my thought processes and remind myself that I can trust my colleagues and ask for their help and guidance as necessary. If I can remember that I am not just seeking guidance for myself but for my family, and Nancy, then I will be able to advocate for our needs better. By putting my family’s need for information first I will find it easier to break through my own fears about how my uncertainty will be interpreted.

What other nurses could learn from these experiences would be to remember assessing the mental health of their clients is not only for those that work within that specialty. Ensuring the mental, emotional and spiritual health of our clients is just as important in all areas of healthcare including medical and surgical nursing. There is also a need for nurses to look inside themselves and ask how they feel about caring for a client who is also a nurse and then ask how they think that nurse-client is feeling about being on the receiving end of caregiving. This would allow the nurse to be more self-aware and empathetic towards their nurse-clients. Lastly appropriate resources for the families of children with severe allergies is needed. Hospitals and General Practitioners offices need to be equipped for how to best manage the child and their family alongside their allergy. Further insights and recommendations are discussed in greater detail in Chapter 6, under the sub-heading ‘recommendations’.

### Who is supporting us?

This theme is three-fold. Within this question I am asking;

- Who is supporting us as a family?
- Who is supporting Nancy, as she grows, goes to school and lives within a community?
- Who is supporting me?

A lack of guidance from the medical profession and differing (sometimes contradictory) instructions about allergy management, are standout themes within my narrative. I discuss my frustrations with the medical team, with my extended family and the wider community through many sections of my narrative. Nancy's first exposure to eggs was following advice from the Plunket nurse, which differed from the advice the Plunket nurses gave our parents when Eddie and I were infants. Although I am aware that new research leads to new advice, it does not stop me feeling an element of frustration with all the conflicting information. As I stated in my narrative, I cannot help wondering that if Nancy had been exposed to egg yolk separately before egg white, as was the advice when Eddie and I were infants, her body would have learnt to recognise the different protein molecules without initiating an allergic response.

My frustration with medical advice increased when our paediatrician said it would be fine for me to continue to eat eggs and breastfeed but everyone, friends with children who also had allergies, people in forums and family members all said I should refrain. I guess, to the doctor, I was just another over-anxious mother of a child with allergies, but from my perspective, I was terrified that if I did the wrong thing I could harm my child. Reflecting on this moment I can recognise that was when I began to wean Nancy from breastfeeding. Her first reaction was when she was eight months old, I had finished breastfeeding by the time she was ten months old. I can remember saying to a friend that 'breastfeeding was such a tie, this would be a good excuse to stop,' but reading back on this I cannot help but feel a little bit sad. I had wanted to breastfeed for at least one year, did this conflicting information encourage me to stop? Was my decision to wean Nancy a result of fear of what I believed to be the unknown? No one could say for sure that it was safe to continue to eat a full diet and there was no consensus that it wasn't.

There was also little guidance, from the medical fraternity, about the purchasing of EpiPens for Nancy. We spent hundreds of dollars buying these because we thought they would save her life if she had a severe reaction, only to find out that she was too young, underweight, and we would have overdosed her had we used one. I am unsure if this is still common practice or if this was just a 'one-off' incident, however as EpiPens and other adrenaline auto-injectors can be purchased without prescriptions, it will remain a potential risk.

There were so many unanswered questions. Do we keep our dog, do we give her away? Can we trust other people and school staff to care for our baby or do we cocoon her? How can we trust school administrations when New Zealand government policy allows for children with allergies to be deemed 'too risky', thus permitting schools to decline their admission? How can we trust caregivers when even we make mistakes, and there is no one to teach them? All of these issues bounce around in my head, building up my levels of frustration and anger, leading me to feeling that my family is isolated and alone in our struggle to learn how to live with a severely allergic child. I fear for Nancy's future. How will she manage when there is no onus on public schools to equip themselves with the knowledge and means to treat severe allergies? How will she cope with the increasing independence that comes with growing up? She will have to self-monitor all of her foods and carry around antihistamines, asthma inhalers and an auto-injector. She will need to be vigilant asking what ingredients are in foods when staying at friends' houses or out on a date. Who is going to teach me how to teach Nancy about how important all of this is, especially as she reaches the vulnerable young adult stages. Who can teach me all of that information when no one appears capable of instructing me now on how to manage allergies?

So to place my nurse researcher's hat on and evaluate these experiences and the resulting emotions involves me taking a deep breath, walking away from my computer then returning to reread what I have written and starting again. The 'good' side of these experiences would be recognising that there is a saturation of advice. There is the internet, the medical team, help groups and forums, friends who have children with allergies, people who have gone through all of this before and have paved the way. There are a multitude of places to go to seek advice. The 'bad' side of these experiences is that with this saturation of advice, it is obvious there are differing opinions and conflicting information. 'Latest'

research can differ completely from research written just a short time before, which can add further to feelings of frustration and confusion.

Step four of Gibbs' (1988) model is to analyse these experiences. In the process of identifying the different factors that affected the outcomes of these experiences, I recognise that the lack of clear guidance from the medical team when Nancy was first diagnosed lead me to seek advice from alternative sources. Even within this medical team there were differing opinions and advice. Although support groups and the internet can be a great source of information it can also hinder your ability to recognise what are facts and valuable recommendations and what is not. One of my main sources of support was friends who also had children with allergies. We all learnt from each other's triumphs and mistakes, and supported each other. Although at times this was like the blind leading the blind.

What else could I have done? I guess I could have asked the doctor to justify why he recommended me to purchase several EpiPens when they were not a suitable prescription for Nancy. I may have heard his response and agreed or I may have felt validated that I had made him aware of his error, preventing it happening to other families. I also could have stated to the doctors or paediatric outreach nurses that I wanted more education and advice about which support groups or internet sources I should use, and ask if the hospital generally referred families to a dietician. However it is only through my journey that I can recognise these points, and the steps that would have benefitted me and my family.

Finally, what is my action plan? My action plan is to increase people's knowledge about allergies and what it is like to live with them. I have started that by writing my thesis about our journey so far. My hope is that through increasing people's awareness I can initiate steps to make the road easier for parents with children diagnosed with allergies in the future.

I would like to further my action plan by addressing all of the above-mentioned points with my local hospital and see if I can get an information pack designed for parents, alongside a clinical pathway which the medical team initiate and distribute to families when a child comes in with an allergic reaction. This could address issues such as providing injection instruction and refresher courses for parents, dietician referrals and the like. These would

all be actioned prior to the discharge of the child experiencing the reaction. Information packs would include local support groups and recommended reliable internet sites, journals, actions plans for what to do if you suspect your child has been exposed to an allergen.

With that said I do find myself asking the question, is this part of my action plan too grandiose? Is this an effective management plan when the environment in which I look to operate it in is not conducive to see it activated. Am I better to work within my sphere of influence? For the for mentioned action plan to work I require District Health Board buy in and whilst I know that can often be easier said than done my internal dialogue is reminding me that everything has to start somewhere.

#### Desperately seeking knowledge

During the writing of this research I had to seek advice from my principal supervisor about the types of information I could use. I found I was using quotes stated by pop stars and using blogs sites within an academic thesis. This is something I would never normally do. I instruct my undergraduate students not to fall victim to the internet, to only use scholarly, peer reviewed research or sources when researching information or writing academic essays and the like. However I included these because I think it highlights how, at that time in my life, I was going against what I know and what I teach. I was desperately seeking any information that could help us in our journey as parents of a child with severe allergies. I was struggling to deal with the conflicting information and a lack of clear guidance.

As I have stated previously, I have been down many different paths seeking information including the internet, medical teams, forums, blog sites, and friends. All of these sources provided advice, things to do, things not to do. The overarching issue for me was no one could tell me what, out of all of this information, was most valuable. I struggled to determine who I should listen to. Lauritzen (2004) discusses how there is a constant stream of new information about allergies from the media and discussed in health care, but that the nature of this information is often contradictory to earlier information given to parents adding to feelings of confusion and frustration.

For the best part there has been elements of trust and of trial and error that has gone into raising Nancy. For example packaged food usually have stated on the back of a packet that



it either 'contains traces of...' 'contains...' or 'may contain...' such ingredients as eggs or nuts. The medical advice I received was just to avoid all egg, nut and peanut products but a friend told me that the statement 'may contain...' simply meant that whatever product it was, was made on the same line as something with egg, nuts or peanuts in it. Following that, I tried feeding Nancy a food product that had 'may contain...' written on the packet. Nancy had no allergic reaction. Reflecting on this makes me shake my head with wonder. Was it just easier for the medical team to simply state 'avoid these foods' or was it risky of me to put Nancy at a degree of risk by trying these foods? Our family diet is so restricted, even when allowing those foods, I cannot imagine how hard it would have been if we continued to avoid them.

The question all of this leaves me with is, who has the most accurate information? For example two different paediatricians we have seen both offered different recommendations regarding the purchasing of adrenaline auto-injectors. I did not find my General Practitioner overly helpful when I asked for advice about starting Edwin on solid foods. When I typed 'managing children with severe allergies' into Google I got 'about 21 100 000' results. All of this left me asking myself when is too much too much, and how do I know where to go for the right information? So much information, but who has the knowledge?

Steps four and five of Gibbs' (1988) model asks me to reflect on those experiences and what else I could have done. I don't think I have the answer for this question. I cannot change the fact that each day there will be more and more information loaded onto the internet. I cannot change the fact that different professionals will disagree, and all will argue for what they think is right. And I cannot change the fact that no one can yet answer the questions I have about allergies. All I can do is monitor how and what information I choose to read and what advice I will follow. I can become better at questioning advice and validating what I read. I will still look at the internet for advice and research but I will do so critically and with stringent search perimeters in place. But should that be the parent's responsibility? Or should the relevant information be collated and distributed on diagnosis?

### **Summary**

Streubert Speziale and Rinaldi Carpenter (2003) believe that providing a summary and making recommendations is an important stage of analysis, this is where the narrative is

given meaning. From reading through my narrative and analysis, the implications for nursing which immediately present themselves to me are how to address and care for families as a whole, mindful of how they are going to function on discharge and when a nurse becomes a client. There is also a need for more research into the area of allergies and allergy management.

I have discussed feeling as though we were treated and discharged and then left to figure out how to manage Nancy's allergies through a series of trial and error. When we got it wrong admissions to the hospital left us feeling judged and that we were failing as parents. So much can be communicated through one insensitive statement or abrupt body language. Admissions are a time to support and an opportune time to educate. Instead, after our experiences of admissions to hospital, we were usually left feeling deflated and inadequate. Crisp and Taylor (2009) believe that when nurses are involved in the treatment of families as opposed to patients, they need to communicate with an additional awareness and understanding of the complexities of family dynamics, needs and relationships. Although only one member of the family may be receiving medical treatment, the whole family is experiencing an emotional response; the implication of the required medical care needs to be addressed by health care members (Crisp & Taylor, 2009).

As a family we brought a range of complexities with us to the health care system. Eddie and I were both recovering emotionally from my recent cancer diagnosis and treatment, this left both of us harbouring fears about what was the underlying cause of Nancy's allergies and illnesses. When you go through treatment for cancer it is a moment of great fear and powerlessness in many ways. I now see that these feelings may have left us unable to use our voices the way we once might have. I think this highlights a need for nurses to be mindful that families may have more in their medical history that impacts on their ability to cope with the current situation at hand. Hockenberry and Wilson (2011) recognize that a parent's previous medical experience may influence their ability to cope when a child experiences illness or hospitalisation. This, alongside a number of other factors, can lead to feelings of fear, anxiety and frustration. Hockenberry and Wilson (2011) believe that left unresolved, these feelings can lead to physical and mental exhaustion and depression. Hospital staff had commented to me that I was 'doing a good job' but I cannot remember being asked specifically 'how I was feeling or coping'.

I believe that during the 'crisis' phase of an admission this question may be wasted. My focus was solely on Nancy during those phases but if I could have been asked this on my own without my husband or child with me, in follow up or prior to discharge I may have given a more honest response. Nurses need to ensure that the emotional needs of the family are addressed, alongside the physical needs of the child experiencing illness.

Another complexity I brought to the experience of raising a child with severe allergies was an immense amount of 'mothers' guilt'. As discussed earlier this can be the norm for a lot of mothers but my medical history coupled with Nancy's hospitalisations increased those feelings of guilt. It is necessary that nurses who treat families are aware of the potential for, and enormity of, 'mothers' guilt' and how that can impact on the mother and her ability to utilize normal coping mechanisms. Hockenberry and Wilson (2011) believes that these feelings of guilt and inadequacy can be minimized by visualizing the family as a whole, as the designated patient and by providing emotional support, listening to parents verbal and non-verbal messages. I think for me, basic empathy would have gone a long way. If someone had used empathy when educating us or asking me how I was coping I may have found some of the support I felt I was lacking.

The final complexity in our case was the fact that I am a registered nurse. There is a need for nurses to be aware that they are not just dealing with another nurse when they have a client who is also a nurse or colleague. My story highlighted fears of wanting to continue to be a well-respected nurse and how these fears inhibited me from asking for further guidance or support. This reaction would be one worth further research. We, as nurses, need to know if we are addressing our own needs when we are health service clients. If my fears are consistent with those experienced by other nurses in a similar situation then this is an area where change is required. Lane-Krebs (2011) argues that when a nurse becomes a client, feelings of guilt and turmoil can prevent her asking for the help she requires. Nurses who are treating other nurses need to be aware that this could be a potential block in nurses accessing full health services. There is also a need for nurses to address their own feelings about how they feel when they have a client who is also a nurse or colleague. My analysis cited research and personal experience where clients felt ignored or left on their own because of an assumption that they would know how to cope or because the nurse responsible for their care was intimidated and afraid of being negatively critiqued.

When I started the journey of writing my thesis my focus was always going to be allergies and allergy management. I was not far through the process of my literature search when the thought presented itself of researching the parents' perspective through my own story. However as I read through my narrative and summary, it becomes apparent that although allergies is the main focus, so much of this is about being a mother and raising a child with complex needs. I would argue that many of these experiences would be similar to those experienced by other parents of children with chronic conditions or parents who also work in the health system. Throughout my summary I have identified lessons that I feel are important for all health professionals to be aware of.

## Chapter 6

### Conclusion

*"I have come to the conclusion, after many years of sometimes sad experience that you cannot come to any conclusion at all."*

V. Sackville-West: 'In Your Garden Again' (1951-1958)

This story not only represents 18 months of research but more than that, it is my journey into parenthood and how I am learning to manage my daughter's severe allergies. As identified in my literature review this is an area where there is an abundance of research but yet still so much remains unknown as to the causes of allergies, the reason why it appears so many more people and children are being diagnosed with allergies, and how to best manage those allergies. I do not know why Nancy developed allergies I do not know if my history or if anything I did whilst pregnant impacted on Nancy's ability to tolerate all foods. I cannot answer why so many more children are developing allergies at a higher level of severity than ever before. I cannot tell you the best way in which to manage allergies. This research has not answered any of those questions, but it does recount the impact of a child's allergies on one family. I have detailed how lost and forgotten I have felt within New Zealand's health and education systems. I have highlighted the increasing number of children developing allergies throughout the world and how we need to better cater for them and their families. Through the exploration of raising a child in New Zealand with severe allergies my story has highlighted many shortcomings with regards to medical management and education, and how community responses could have been better. Different responses may have helped us feel less alone, unsafe, judged, scared or frustrated because we were living with severe allergies.

Through using autoethnography for this thesis I was able to provide a deeply personal insight into the impact allergies can have on both the child with the allergies, the child's family as a whole and to a lesser extent, the child's community. Producing autoethnographic research has provided a number of challenges. One of the main challenges I found writing in this manner was recognising what elements of my story were of value and worthy of analysis. Therefore keeping my work scholarly and accepted by my peers in the health profession. Also deciphering what, from my life, is of relevance and interest to a wider audience and allowing myself to write in a manner that encourages the incorporation of myself and my emotions in the research. Gibbs' (1988) model of reflection has been widely

used within nursing. By using this model for my analysis I have demonstrated how autoethnography and personal narratives can be relevant and insightful methods of research within nursing.

My story has taken me from independent, professional woman to mother and back again. It has detailed the road I travelled along with my own health, that of my family's and how we have adapted to life with allergies. My story has highlighted how at times I was my own worst enemy, wanting to keep up appearances and refusing to ask for help whilst internally crying out for it. Through the process of analysing my own experiences I have come to see some of my own shortcomings and my internal negative dialogue. I now recognise the traits I have that block my ability to ask for help and can now start the process of addressing them.

The main motivation for writing of my experiences was to increase knowledge about the impact of allergies on families and to change the public perception of allergies that I have become so familiar with. Allergies are neither the end of the world nor are they as easy to deal with as seasonal hay fever. The impact of allergies on a family is constant and through making more people aware of this we can start to initiate change where it is most needed. More resources are needed so families of children with allergies can afford the best treatment, such as adrenaline auto-injectors and more research is needed in this area. The action plan I have outlined in my recommendations is something I believe will help ease the journey for families living with a child or children with allergies.

### **Limitations**

The findings of this research are based on the experiences of one person caring for one child. This could be considered a limitation. However they address a widespread health, medical and nursing issue which is seemingly growing. Most international literature agrees that allergies are increasing substantially and this belief is shared by Allergy New Zealand (2012b). If another parent was to write an autoethnographic narrative about raising a child with allergies there may be many differences. This would be due to differences in the nature of the allergy. Differences within each person's history, culture, values, income, alongside access to healthcare. These differences may lead one to questioning the validity and merit of these types of qualitative studies believing that they cannot be viewed as a 'true' science. However as Streubert Speziale and Rinaldi Carpenter (2003) discuss, this is precisely the reason why qualitative research methods have merit. They allow for a

context-bound view of phenomenon. In this case, the phenomena is that of being a mother raising a child with severe allergies. This method allows the reader to learn about, not *the* truth, but *a* truth.

There are limitations with the use of Gibbs' (1988) model of reflection as a tool for the analysis of life's experiences. Whilst on the surface this model gains background knowledge through reflection in order to establish a management plan, it does not seem to take into account the sociocultural environment in which it is embedded. This information has the potential to effect the prescribed action plan.

A further limitation could be that these are not just the experiences of one person but they are experiences within one health care organisation of New Zealand. Primarily our experiences concerned one general practitioner and one public hospital, which begs the question, would these experiences resonate with those of others parents or caregivers in other regions of the country? What happens in other organisations? My experience to date leads me to believe that the problems we experienced are widespread, not just throughout New Zealand but also internationally. Research conducted within the North Island of New Zealand by McBride et al. (2010) discussed the significant rise of children with medically diagnosed severe allergies in western countries. Their findings were very similar to my own. Their research highlighted that the experience of parenting a child with severe allergies in New Zealand is one of feeling isolated and being unsupported. Parents felt unable to access appropriate resources and the added financial cost of living with severe allergies added to their frustrations. McBride et al. (2010) called for national clinical practice guidelines to ensure consistent and effective care for children and their families.

The final limitation is that this research could be viewed as Eurocentric. It does not discuss the bicultural and multiracial mix of New Zealand and how allergies may impact on different communities or cultures. For a large part this research builds on that conducted by McBride et al. (2010). Both pieces of research discuss families where the parents are married, European and from a middle to upper class socio-economic households.

### **Recommendations**

Recommendations are included to add value to the research (Streubert Speziale & Rinaldi Carpenter, 2003). The following section highlights what was the aim of the research and

how my experience can better inform practice? Throughout the analysis I have made mention of recurring themes and made suggestions about how our care and treatment could have been improved, thus avoiding the flow on feelings of frustration and inadequacy that we went through. These recommendations will now be stated with the hope that the initiation of some or all of these will go some way to ensuring parents and caregivers have a better experience than we did when a child is diagnosed with severe allergies.

To be diagnosed with a severe allergy is not a death sentence nor does it mean that the family will need to live a life of exclusion if it is appropriately managed in the first instance. Allergy New Zealand (2012b) calls for the funding of adrenaline auto-injectors. This is the first of my recommendations. I believe that Government funded auto-injectors is imperative and can mean the difference between life and death if an anaphylactic reaction occurs. Adrenaline auto-injectors also provide an element of security for families and caregivers when a child with allergies engages in the community and need to be accessible for all regardless of socio-economic status.

I recommend that when allergies are diagnosed and treated in a hospital or general practitioner's office there should then be a care pathway initiated. This would involve an education pack provided for the parents to take home, alongside basic education and recommendations at the time of diagnosis so parents or caregivers know what to do on discharge. Alongside that, a referral should be actioned for a follow-up service operated through either the health consumer's general practice nurses or hospital outreach nurses. I believe this is an unrealistic expectation to place on the parents of a child diagnosed with severe allergies to search through and collate this information themselves given the breadth and contradictions in what's out there. Not to mention the cost of getting it wrong.

For this to be effective there needs to be more education for nurses about allergies and allergy management. Education could include an introduction to allergy management within undergraduate nursing education curricula. Following on from that, specialist training courses within post graduate education would enhance nurses' knowledge and could lead on to the creation of a specialist nursing roles within allergy management. I recommend that this role needs to be established and requires support from paediatricians and dieticians. It needs a multidisciplinary approach to construct and action. This specialist role could span both hospital and primary health environments. Education packs that would be given to families on diagnosis of an allergy would include information about:



- How to recognise and treat the early signs of an allergic reaction specific to the reactions experienced including how to recognise the early signs that the child is entering an anaphylactic episode and requires the administration of adrenaline (ideally through the use of a funded adrenaline auto-injector). The literature highlighted that many parents and caregivers often delay the administration of the adrenaline auto-injector for one of two reasons, either they are frugally trying to save the expensive equipment or they have failed to recognise the early symptoms as anaphylaxis.
- Specifics about how to use the adrenaline auto-injector or manual needle system, including information about how to ensure that the adrenaline maintains potency and has not expired. Information that educates about the importance of always carrying their adrenaline and other treatment options such as anti-histamines. How to keep these safe so as not to be accessed by other children unnecessarily and how to educate other family or community members that may take responsibility for the care of the child with allergies, for example teachers, coaches, scout leaders, and babysitters.
- Specifics about what the allergy means for that child. For example an allergy to whole eggs requires the avoidance of all egg products, cooked, raw and egg powders, whereas children who are allergic to egg yolk may be able to tolerate egg whites as found in mayonnaise.
- The importance of reading all food labels and how to do this including what they mean. Providing further education about the fact that different companies can make the same food with different ingredients so as to ensure parents do not get complacent about the packaged food.
- How to ensure children's nutritional requirements are met whilst avoiding certain food groups. For example ensuring that children with dairy allergies still maintain their required amount of calcium.
- The potential for co-morbidities such as asthma or eczema. How to recognise these and what to do if one of these is believed to be occurring. How to treat these co-morbidities.
- How to function in a community when you have life-threatening allergies. This would include information about recognising that when you include your child in community or group activities you may have to bring your own food. Ensuring allergy friendly-food is always accessible is a must for families of

children with allergies. This may mean keeping a supply of non-perishable food in the car.

- Finally it would include information about different activities that the child would be better to avoid. For example children with peanut allergies should not pick up litter in case they come into contact with a product used to cover peanuts or peanut butter.

I also recommend that all families are provided with a one-off intensive education session on diagnosis of a severe allergy. Following this, annual visits would be required to reissue adrenaline (for either the auto-injector or manual draw up technique). This would assist in ensuring compliance and confidence in administering adrenaline via the chosen method. It would be an appropriate time to give tailored education depending of the child's developmental stage. This would include how to teach caregivers or parents about introducing new foods and how to teach parents and caregivers about educating their children about their allergies and when is a right time for that child to take responsibility for their allergy management. This would also be an opportune time to help parents or caregivers to cope with the diagnosis emotionally, mentally and practically. Morgan and Simmons (2009) believe that the New Zealand government is investing in a false economy by treating conditions in hospital as opposed to preventing the need for hospitalisation in the first instance. The establishment these allergy management initiatives is recommended in a hope that through adequate and regular education less children will be exposed to their allergens resulting in fewer hospital visits.

There is also a need to have the child's school involved in the management of their allergies. This would entail, ideally, a visit to the school by a nurse or health professional involved in the care of that child's allergies to ensure that they have at least one person on staff who is trained and equipped to manage an allergic reaction should one occur. It would also be a time to educate schools about the complexities of having a child with allergies within the school and to leave a resource pack similar to the one parents would receive. This would ideally be done in conjunction with the parents so as to provide them with some reassurance that their child will be well looked after when in the care of the school.

### **Implications for further research**

I am driven to start the process of change within the management of allergies in children. As previously mentioned, within the field of allergies there is little current research completed within the New Zealand context. In order for people to want to research this

area more people need to be aware of the need. To support this, issues concerning allergies and allergy management need a larger audience. There is a need for further research utilizing quantitative research methodologies to provide nationwide statistics regarding the extent and health care implications of allergies in New Zealand.

More research is required which gathers statistics on children diagnosed with allergies and the severity of their allergies. We need to know what method of treatment parents typically opt for, whether it be auto-injectors at their own cost or the publically funded needle and ampule system, plus the reasons for their choice and the implications. This information would assist policy development regarding best practice. This is required so, as a nation, we can ensure all children are able to receive best treatment options. It would also provide statistics on how many more children are living with allergies, to understand if this rate is increasing and if so, to what extent. This information is required so we can prepare for and cater for the needs of these children and future generations.

Further research about the experiences of families when a child is diagnosed with an allergy or other chronic illness. This could focus on the emotional impact of such a diagnosis and the impact on parents or caregiver's ability to cope with a child experiencing illness. More research could also be done looking at the impact of being a nurse or health professional who is also a parent of a child with medically diagnosed severe allergies or chronic illness, combined with research into how to care for a nurse who is also a health care consumer.

### **Implications for nursing practice**

One of the goals of conducting research and reporting the findings is that they will serve to better inform practice. These implications involve not just changes to practice but also reaffirming a lot of the content that is covered in nursing training. This study has identified three key issues that should impact on nursing practice. Firstly, the lack of consistent information about how to best manage and treat allergies in children. Secondly, how better support from the medical profession can positively affect the family's ability to cope with the allergies both medically and emotionally, and finally, how education can better serve the family.

This research identified that a specialised nursing role would assist in promoting harmony between different health disciplines and the family involved. Through this role and the initiation of a clear allergy pathway we can meet the needs of both the health professionals involved in the care, and the needs of the family. The priorities of physicians and the health care team to ensure that the allergies are being well managed, alongside the holistic needs of the family would be addressed through this nursing role. It would also assist in ensuring consistent, current and relevant information was being supplied to families. Another benefit of this role would be that families would know where to go if they had new concerns or questions. This would bypass the often extended waiting time to see a pediatrician through the public health system.

Nurses are members of a multi-disciplinary team who generally spend the most time with patients. It would be of benefit to all involved to better utilize this relationship. However when working with children with chronic conditions, such as severe allergies, it is important nurses recognise the child is not their only patient. Instead they need to view the whole family unit as their patient. With this in mind nurses need to address the needs of that family. Whilst treating the condition is of paramount importance, this study identified that what is also of great importance is minimizing disruption to normal family life. By recognising that the whole family is their patient, nurses can start to empathize more with the relentless weariness that comes when a member of the family has a condition that warrants constant vigilance and supervision. Recognising that this constant vigilance will impact on family dynamics and the family's ability to manage their lives. This study identified that it was this constant fear and need for safety that contributed to added stress and emotional strain. This impacts not only on how the family functions with day-to-day life within a community, but also on how they manage said condition(s). By being aware of, and allowing for this within their nursing practice nurses will strengthen their therapeutic relationship with affected families.

Nurses need to recognise that they are more than 'health professionals', they are also 'health educators'. Within this role nurses can gain advantage from the fact that they have direct contact with patients, whanau/family, and community members. This study makes the recommendation for resource packages for parents, and annual recalls for updating education and allergy treatment options. This initiative has the potential to be nurse led. International research suggests that allergies have increased sevenfold (Dunbar & Luyt,

2011). If this continues then there is the future potential for allergy management to become a nursing specialty practice area. However this would require more research of both qualitative and quantitative methodologies conducted by nurses.

### **The final word**

This is an opportune time to address some of the initial question I asked in my opening chapter. Am I a good parent? Am I a good mother? Was it my fault?

- Am I a good parent?

I am fortunate to have Eddie as my partner. Together we are good parents. We support each other and communicate our concerns together. Eddie allows me time out when I need it and encourages me, he makes me a more 'fun' parent. I feel that I am a good parent because I have him by my side.

Since becoming a parent I find myself in awe of the single parent families that travel this road without that constant support.

- Am I a good mother?

I find this so difficult to answer, when really it shouldn't be. Why do I feel like I am boasting if I answer yes to this? I guess if I was to be logical about it I just need to look at Nancy and Edwin. They are so loved, they are happy, they know their boundaries and are constantly testing them. Yes I am a good mother, maybe even better than just 'good'.

- Was it my fault?

Nobody really knows yet what causes allergies, but if I only listen to the logical part of my brain then I know that it is not my fault. Even if new research proves that something I did whilst pregnant caused Nancy's' allergies, I still know that it is not my fault. I know that throughout Nancy's pregnancy and childhood I have never done anything that would intentionally harm her. I have always sought best advice to ensure her physical, emotional and spiritual wellbeing.

Given the amount of information about Nancy's' allergies that I have shared using my own voice and story I feel it is only fitting to allow Nancy to have the final word about what it is like to live with allergies.

"I don't like having allergies, especially when other kids get to have cake and I don't"

## **Epilogue**

Towards the end of writing this thesis Nancy was unintentionally exposed to egg. This was a harrowing and scary time. I surrounded Nancy with antihistamines, inhalers and her EpiPen and waited. However no adverse reaction occurred. I went back to the recipe of the food she had eaten and the ingredients noting that, yes eggs were present. I monitored her closely for a delayed reaction all night but in the morning it was as if nothing at all had happened. Her latest RAST test had noted a moderate allergy to egg but due to this exposure the medical team decided to trial her with egg in baking.

Nancy went through another barrage of tests. I cannot describe how scary this was. It could potentially be another thesis. In summary, Nancy went on to trial egg in baking, followed by almonds and then a whole egg. We still have a multitude of nuts to trial and peanuts (to which she is still showing a moderate-high allergy) but all signs are that Nancy is growing out of her allergies.

I can remember hiding my tears and fears from Nancy as we left for the hospital to trial the egg. I was terrified of a reaction. When she showed no reaction it was a weird feeling. I felt a bit lost. Her allergies have consumed my thoughts for four years and now it would appear that they are no longer going to be such a large part of our lives. In saying that, there is still no room for complacency.

When Nancy was first diagnosed with severe allergies I asked if she would grow out of them, as infuriatingly, it seemed everyone I met said she would. Our paediatrician believed that although a large number of children do outgrow their allergies, Nancy's reaction was so severe he did not think she would.

The first meal Nancy wanted to try after we discovered she could eat eggs was bacon and eggs. I think she only ate three or four mouthfuls when she asked if she could swap my bacon for her egg. She is just like her father.

## References

- Allergy New Zealand. (2012a). *2012 report. What is the prevalence of food allergy in New Zealand?* New Zealand Author. Retrieved from <http://www.allergy.org.nz/site/allergynz/What%20is%20the%20prevalence%20of%20food%20allergy%20in%20New%20Zealand.pdf>.
- Allergy New Zealand. (2012b). *Allergy New Zealand's Annual Report 2011-2012*. New Zealand: Author.
- Beanland, C., Schneider, Z., LoBiondo-Wood, G., Haber, J. (1999). *Nursing Research*. Melbourne, NSW: Mosby.
- Bennett, L. (2004). Food allergens and food allergy-complex relationships and responsibilities. *Nutrition and Dietetics*, 61(2) 73-75.
- Brantlee Broome-Stone. S. (2012). The psychosocial impact of life-threatening childhood food allergies. *Paediatric Nursing*, 38(6) 237-330.
- Braun, C., & Anderson, C. (2011). *Pathophysiology. A clinical approach* (2<sup>nd</sup> ed.). Philadelphia, USA: Lippincott Williams & Wilkins.
- Brodesser-Akner, T. (2013.10). Hot Pink. *Australian Women's Health*, 2013(October), 84-87.
- Burns, N., & Grove, S. (2009). *The practice of nursing research*. (6<sup>th</sup> ed.). St Louis: Saunders Elsevier.
- Burrows, D. (1995). A nurse teacher's experience in the promotion of reflective practice. *Nurse Education Today*. 15 (346-350).
- Chang, H. (2008). *Autoethnography as a Method*. Walnut Creek, CA: Left Coast Press.
- Chaperon, Y. (2010). Caring for nurses and midwives. *Australian Nursing Journal*, 18(4), 20.
- Chrisp, J. & Taylor, C. (2009). *Potter and Perry's fundamentals of nursing*. (7<sup>th</sup> ed). New South Wales: Mosby Elsevier.
- Christie, R. & Street, T. (2013. May 13). *Allergy Awareness week*. Breakfast: New Zealand: TVNZ ondemand. Retrieved from <http://tvnz.co.nz/breakfast-news/allergy-awareness-week-video-5435317>.
- Coffey, A. & Atkinson, P. (1996). *Making Sense of Qualitative Narrative: Complementary Research Strategies*, Thousand Oaks Sage Publications, Inc. CA.
- Denzin, N., & Lincoln, Y. (2005). *The sage handbook of qualitative research* (3<sup>rd</sup> ed.). Thousand Oaks, CA: Sage Publications.
- Dunbar. H. & Luyt. D. (2011). Triggers, clinical features and management of anaphylaxis in children. *Nursing Children and Young People*. 23(5) 29-35.

- Edwards George, J. & McQuaid, E. (2010). Considering the psychosocial aspects of paediatric food allergies. *The Brown University Child and Adolescent Behaviour Letter*, 26(11) 2-6. Doi:10.1002/cbl.20127.
- Ellingson, Laura. L., & Ellis, C. (2008). Autoethnography as constructionist project. In J. A. Holstein & J. F. Gubrium (Eds.), *Handbook of constructionist research* (pp. 445-466). New York: Guilford Press.
- Ellis, C. (1997). Evocative Autoethnography: Writing emotionally about our lives. In W. G. Tierney & L. Y. Lincoln (Eds.), *Representation and the Text. Re-framing the narrative voice* (pp. 114-139). New York: Albany.
- Food and Drug Administration. (2012). *Food Allergies: Reducing the Risks*. Retrieved from URL <http://www.fda.gov/ForConsumers/ConsumerUpdates/ucm089307.htm>.
- Galloway, M. (2012). Allergy in Children. *Practice Nurse*, 42 (6).
- Ford, G. (2001). *The Contented Little Baby Book: The secret of calm, confident parenting*. United Kingdom: NAL Trade.
- Forssen, A., & Carlstedt, G. (2006). "It's heavenly to be alone!" A room of one's own as a health-promoting resource for women. Results from a qualitative study. *Scandinavian Journal of Public Health*, 34(2), 175-181.
- Foster, K., Mc Allister, M., & O'Brien. (2006). Extending the boundaries: Autoethnography as an emergent method in mental health nursing research. *International Journal of Mental Health Nursing*, (15), 44-53. Doi: 10.1111/j.1447-0349.2006.00402.x
- Galloway, M. (2012). Allergy in Children. *Practice Nurse*, 42 (6).
- Gatfield, J. (2010). *Stepping away from the ring: an autoethnographic study of hero worship created through media worship through media consumption* (unpublished Masters' thesis). Boise State University, Idaho: USA.
- Gibbs, G. (1988). *Learning by doing: a guide to teaching and learning methods*. Retrieved from <http://www.2glos.ac.uk/gdn/gibbs/>.
- Health and Disability Commissioner. (2009) *Health and Disability Commissioner*. Retrieved from [http://www.hdc.org.nz/theact-code-of-rigths/the-code-\(full\)](http://www.hdc.org.nz/theact-code-of-rigths/the-code-(full)).
- Hockenberry, M. & Wilson, D. (2011). *Wong's nursing care of infants and children*. (9<sup>th</sup> ed). Missouri: Mosby Elsevier.
- Hurwitz, B., & Charon, R. (2013). A narrative future for health care. *The Lancet*, (381), 1886-1887.
- Johnson, B. & Webber, P. (2005). *An introduction to theory and reasoning in nursing*. (2<sup>nd</sup> ed.). Sydney: Lippincott Williams & Wilkins.



- Kahn, S. (2011). Putting ethnographic writing in context. In C. Lowe & Z. Pavel (Eds.), *Writing Spaces: Readings on writing* (p.175-192). San Francisco, CA.
- Keane, P., Hurring, K., Forrest, V. & Mc Callum, K. (2012. Jun. 22). *Essential Epi-pen not funded*. Campbell Live. New Zealand: TVNZ on demand. Retrieved from <http://www.3news.co.nz/Essential-EpiPen-not-funded/tabid/817/articleID/258769/Default.aspx>.
- Lauritzen. S. (2004). Lay voices on allergic conditions in children: parent's narratives and negotiation of a diagnosis. *Social Science & Medicine*, 58 (2004) 1299-1308.
- Lane-Krebs, K. (2011). Dual roles and conflict: nurses as mothers of critically ill neonate. *Australian Nursing Journal*, 18(9), 37.
- Leask, A. (2009). Call for allergy funding. *The New Zealand Herald*. Retrieved from URL [http://www.nzherald.co.nz/nz/news/article.cfm?c\\_id=1&objectid=10615190](http://www.nzherald.co.nz/nz/news/article.cfm?c_id=1&objectid=10615190).
- Lineham, C. (2001). *Non-participants in physical education: A narrative journey in complexity*. Otago University. Dunedin: New Zealand.
- MacDoctor, (2012). *The pen is mightier than the jab*, Retrieved from URL <http://sciblogs.co.nz/macdoctor/tag/Pharmac/>.
- Maykut, P., & Morehouse, R. (2000). *Beginning Qualitative Research. A philosophic and practical guide*. London: The Falmer Press.
- McBride, C., McBride-Henry, K., & van Wissen, K. (2010). Parenting a child with medically diagnosed severe food allergies in New Zealand: The Experience of being unsupported in keeping their children healthy and safe. *Contemporary Nurse*, 35 (1), 77-87.
- Morgan, G. & Simmons, G. (2009). *Health Cheque: The truth we should all know about New Zealand's Public Health System*. Wellington: Phantom House.
- Oxford Brookes University. (2013). *Reflective Writing: About Gibbs' reflective cycle*. Retrieved from URL <http://www.brookes.ac.uk/services/upgrade/study-skills/reflective-Gibbs'.html>.
- Paweanker, R., Walter Canonica, G., Holgate, S., T., & Lockey, R., F. (2011-2012). *WAO White Book on Allergy 2011-2012: Executive Summary*. World Allergy Organisation.
- Seagram, S., & Daniluk, J. (2002). "It goes with the territory": The meaning and experience of maternal guilt for mothers of preadolescent children. *Women & Therapy*, 25(1), 61-88.
- Shires, B. (1982). When the giver is the receiver. *Nursing*, 12(11), 160.

- Silverman, D. (2000). *Doing qualitative research. A practical handbook*. (1<sup>st</sup> ed.). London: Sage Publications.
- Sohi, D., & Warner, J.O. (2008). Understanding allergy. *Paediatrics and Child Health*, 18(7), 301-308.
- Stewart, M., Masuda, J., Letourneau, N., Anderson, S., & McGhan, S. (2011). "I want to meet other kids like me": Support needs of children with asthma and allergies. *Comprehensive Paediatric Nursing*, (34) 62-78.  
Doi:10.3109/01460862.2011.572638.
- Streubert Speziale, H., & Rinaldi Carpenter, D. (2003). *Qualitative Research in Nursing: Advancing the Humanistic Imperative*. (3<sup>rd</sup> ed.). Philadelphia: Lippincott Williams & Williams.
- Swingart, J. (1998). The myth of the perfect mother: *Parenting without guilt*. Chicago: Contemporary Books.
- University of Kent. (2012). *Reflective learning*. Retrieved from [www.kent.ac.uk/learning/PDP-and-employability/pdp/reflective.html](http://www.kent.ac.uk/learning/PDP-and-employability/pdp/reflective.html).
- Williams, N., Parra, G., & Elkin, T., (2009). Subjective distress and emotional resources in parents of children with food allergy. *Children's Health Care*, 38, 213-227. doi: 10.1080/02739610903038792.
- Wijayatilake, C. (2012). *An autoethnographic inquiry into my teaching practice and experiences as a teacher trainer and beginning principal at two international schools in Sri Lanka*. (Unpublished doctorate thesis). United Kingdom: The University of Warwick. Coventry.
- Williams, N., Parra, G., & Elkin, T. (2009). Subjective distress and emotional resources in parents of children with food allergy. *Children's Health Care*, 38, 213-227. doi:10.1080/02739610903038792.

## Appendices

### Appendix A.

# Gibbs Reflective Cycle

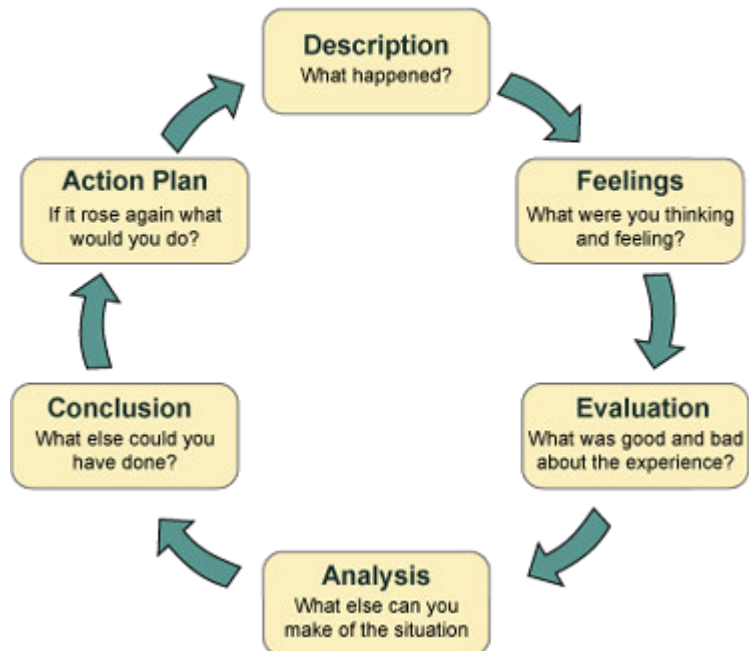


Figure 1: Gibbs' (1988) reflective cycle (University of Kent: Reflective Cycle. 2012)

## Appendix B.

### Research, Ethics and Approvals Committee, Eastern Institute of Technology



Reference Number 16/13

30 July 2013

Cassandra Carstensen  
C/- Faculty of Health Sciences  
EIT

Dear Cassie

Thank you for re-submitting your revised research project. I am pleased to inform you that your research project "*An exploration of raising a child with severe allergies and the potential for an anaphylactic reaction in New Zealand*" was received and approved by the Research Ethics & Approvals Committee at their meeting held on 26 July 2013 for a period of 2 years.

You are reminded that should the proposal change in any significant way, then you must inform the Committee. Please quote the above reference number of all correspondence to the Committee.

The Committee wish you well for the project.

Yours sincerely

**Jeanette Fifield**  
Secretary – Research Ethics & Approvals Committee

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